

“THE GRIEF NEVER GOES AWAY”:  
A STUDY OF MEANING RECONSTRUCTION AND LONG-TERM GRIEF  
IN PARENTS’ NARRATIVES OF PERINATAL LOSS

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By

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Keywords: perinatal loss, long-term grief, meaning reconstruction, narratives

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## ABSTRACT

The purpose of this dissertation was to explore the experience of long term grief following a perinatal loss. In particular, the processes of meaning reconstruction and self-changes stemming from perinatal loss were explored by listening to parents' in-depth narratives of their experiences of loss and grief. A narrative methodology was used, based on a constructivist epistemology that suggests that people are storytellers by nature and we attempt to organize and make sense of our life experiences by constructing coherent narratives. Participants were 4 couples and 8 individuals whose losses occurred 1 to 35 years before the interview. Interviews followed a reflexive-dyadic interview model. Analysis of the narratives was approached in two ways: First, a voice-centered relational approach was used for initial interpretation and identification of prevalent "voices" in the stories. Second, five of the stories were written as "evocative narratives", which served as a way of incorporating the author's personal experience of perinatal loss, as well as to evoke an empathic understanding of the experience of perinatal loss. The interpretation and discussion of the stories focussed on meaning-making that was evident on both an individual level as well as across the larger group of participants. In particular, meaning-making influences and strategies were identified, including influences of the medical establishment and social networks which either served to disenfranchise parents' losses or to comfort and ease parents in their grief. The impact of meaning-making on long-term grief was considered, as well as parents' reports of positive and negative self-changes that emerged from their struggle with grief. The unique contribution of this project lies in its elaboration of the meaning reconstruction process in the context of perinatal loss; its demonstration of both positive and negative self-changes in a group of perinatally-bereaved parents; its exploration of grief several years to decades following a perinatal loss; its inclusion of the researchers' self as both an additional source of data and as a "validity check" on the presentation and interpretation

of participants' stories; and the use of "evocative narratives" to evoke an empathic understanding of a historically disenfranchised form of loss.

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This dissertation is dedicated to

Jacob Leigh

And to the other babies whose parents' stories of love and grief  
are contained in these pages:

Melissa Riel

Abigail Jane

Shawn Allan

Keirin

Christopher-John (C-J)

Brittany

Hannah

Marie, Theresa, and Jane

Gregory

Tasha

Alanna

Reanne

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## 1. INTRODUCTION

*Six years and counting  
You are in my thoughts  
On a daily basis –  
Because of my research  
And because you are my son.  
As long as she has a memory  
A mother cannot forget her child  
Any more than her body can forget its need  
For food, water, air  
At least this mother can't.*

*I don't cry every day  
Like I used to  
I don't look at your things  
Like I used to  
I don't ache every moment  
Like I used to  
But every so often  
Out of the blue  
A memory will grab me  
And I feel a shadow of the anguish  
That I once knew so intimately  
And sometimes  
The anguish returns  
As though it was just yesterday  
That you died before I could say hello  
And I grieve again  
Like I used to.*



When my son, Jacob, was stillborn in September of 1999, I experienced devastation and despair as I never had before and perhaps never will again. It seemed a particularly cruel irony for the normally joyous event of a birth to coincide with the bitterness and darkness of death. Shortly after my loss I began to read anything I could find on pregnancy and perinatal loss<sup>1</sup>. So

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<sup>1</sup> I use the term *perinatal* to refer to the period extending from 20 weeks gestation to the end of the first four weeks after birth. When referring to loss, perinatal refers to stillbirths and neonatal deaths. *Stillbirth* or intrauterine death refers to a foetus/baby born following at least 20 weeks gestation and showing no sign of life at the time of birth. *Neonatal death* is the death of a baby between birth and 28 days of age. *Miscarriage* is the death of a foetus/baby prior to the 20<sup>th</sup> week of pregnancy; approximately 1/3 of all

began my search for meaning in my loss and in my son's too-short life. I questioned why this happened, both from a concrete standpoint and from a more existential point of view. I searched for answers through spirituality. And I tried to create something positive out of my experience as a way of coping with my loss and to make sense out of the senselessness of my baby's brief life in the womb and premature death. Out of the bewilderment of my loss, it was a natural progression for me to decide to study long-term grief and the search for meaning that emerges from a perinatal loss.

Searching for meaning after the death of a loved one appears to be a universal phenomenon and an important part of the grieving process (Davis, 2001; Miles & Crandall, 1983; Parkes & Weiss, 1983; Wheeler, 2001). The trauma, shock, and the anguish of grief shake a person's assumptions of the world to the very core. Searching for meaning in the meaninglessness of a loss is how human beings attempt to re-establish a sense of order and trust in the world, an attempt to minimize one's sense of vulnerability in the face of shattered assumptions about the orderliness and justness of life (Baumeister, 1991; Janoff-Bulman & Frantz, 1997; Nadeau, 1998; Neimeyer, 2001). It is an attempt to find some way, some reason, to go on following the death of a significant person in one's life. Failure to find meaning in a loss, to make sense of it cognitively and emotionally, is said to impede the "recovery" process (Weiss, 1993).

As I developed my thoughts and questions for this project, my own grief process changed and evolved. In addition to searching for concrete answers and more "purpose of life" meanings, I also began to notice transformations and changes in myself: my values, my beliefs, my priorities, my empathy for others, and my general perspective on life. These transformations have not always been permanent. Some have flitted into my life briefly, only to just as quickly leave me; others have come and gone and then returned again in a more permanent way. At times, I have viewed my need to search for meaning in my loss as a natural, automatic process, one that has led to the transformations I have undergone. As the years have passed, I have come to realize that my attempt to make sense of my loss and grief and find positive meaning was more deliberate at times, something I actively pursued. This process of searching and transforming will likely continue indefinitely, in one form or another, throughout my life.

In the early days of this project I discovered that the existing perinatal loss literature did not often, or comprehensively, address the searching and transforming process that I have experienced in my own grief. There are essentially three important literature sources on perinatal

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pregnancies end in miscarriage (Health Canada, 2000). *Pregnancy loss* refers to any type of loss during

loss: traditional quantitative and clinical research and theories; qualitative research; and self-help and popular literature. The majority of traditional quantitative research has been clinically and pathology-oriented, considering such things as the intensity and duration of grief and rates of anxiety and depression at various time periods after a perinatal loss (e.g., Cordell & Thomas, 1997; Janssen, Cuisinier, de-Graauw, & Hoogduin, 1997; Theut et al., 1990). Some of the self-help/popular literature, usually written by parents who themselves experienced perinatal or pregnancy loss, has alluded to the search for meaning and transformations in response to pregnancy and perinatal loss, but has obviously not systematically studied these processes.

It was within the qualitative research base that I began to find some answers to my interest in the meaning-making<sup>2</sup> and transformation process. Although only a few exemplary qualitative or combined quantitative-qualitative studies exist (e.g., Boyle, 1997; DeFrain, Martens, Stork, & Stork, 1990-1991; Gilbert & Smart, 1992; Layne, 1996), these studies have gone far in shedding some light on the depth and intensity of the lived experience of perinatal loss. Studies such as these have identified but not focused on the importance of the search for meaning that parents often go through as part of the grief process. Gilbert and Smart (1992) found that parents began early in their bereavement to search for meaning in their loss, beginning with concrete questions about the cause of death, and moving to more existential or spiritual questions about the meaning of their children's lives and deaths, and about how the world "works" (e.g., realizing that life is vulnerable and the world is not orderly). Clinical case reports have suggested that when parents are unable to find any positive meaning in their experience they are more likely to remain angry, emotionally distressed, and unable to function "normally" for an indefinite period of time (e.g., Leon, 1990; Rando, 1986). Other parents may not have serious psychological disturbances, but remain haunted by unresolved issues surrounding the loss. Boyle (1997) found that some parents reported a number of ongoing struggles with issues of meaning as long as 30 months after their loss. They described themselves as having a difficult time finding a sense of optimism about the future, feeling

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the pregnancy period, including miscarriages and stillbirths.

<sup>2</sup> *Meanings* are defined here as an individual's "cognitive representations...constructed in the [social] context, that symbolically represent various elements of reality. Meanings are the products of interactions with others and are influenced by the context in which they occur, including the influence of society, culture, and historical time." (Nadeau, 1998, p. 14). The *search for meaning or meaning-making process* refers to the attempt to answer questions such as what the significance of an event is, what the event means for the individual's life, and other questions that help to make sense of an adverse event within the context of an individual's larger life experience (Nadeau, 1998). See chapter 9 for a more detailed description of meanings, meaning-making, and meaning reconstruction.

powerlessness in the face of realizing that many life events are not in their control, and feeling that more bad luck would eventually strike again.

On the other hand, some parents have reported experiencing positive changes and personal growth because of their loss (e.g., Borg & Lasker, 1981; Boyle, 1997; Gilbert & Smart, 1992). Boyle (1997) found that some mothers came to recognize their own inner strength, which they were previously unaware of but came to know through their loss experiences. Others felt their self-esteem had been enhanced because of their loss, primarily as a result of being proud of their strength and their conscious decisions to make something positive come out of the loss. And some felt they had become more compassionate people and that their interpersonal relationships had improved because of their changed perspectives and priorities in response to the loss. Out of these findings, Boyle recommended that future studies pursue a deeper understanding of these positive transformation phenomena.

The first aim of this project was to explore the experience of losing a baby in the perinatal period, how parents' grief changed over time, and how they came to find meaning in their experience and undergo personal changes or transformations. A narrative methodology was used, with the intention of revealing the searching and transforming process contained within the narratives that parents constructed for themselves and for others. Parry (1991) suggested that the process of searching for meaning after a loss is a way of "re-storying" one's life to emerge from the pain of meaninglessness, bitterness, and disillusionment. Narrative theorists base their views on a constructivist epistemology, suggesting that people are storytellers by nature and we attempt to organize and make sense of our life experiences by constructing coherent narratives (Neimeyer, 2000). Life experiences that involve trauma and loss disrupt or shatter the foundations of our stories. Narratives, then, are the stories we "tell," explicitly or implicitly, to make sense of such experiences for ourselves and for others. With this in mind, participants in this study were asked to share their narratives of perinatal loss, serving as a window to their meaning-making and personal transformation journey. Approaching such a topic from a qualitative, narrative perspective left open the possibility of hearing both positive stories of renewal and growth, as well as stories that reveal how the grief process is different when positive meaning cannot be found. Following a narrative methodology allowed for treating my participants as the experts (Rosenblatt, 2000), and for their stories to speak for themselves.

What is the process of meaning-making that parents go through after a perinatal death? How do cultural and societal beliefs, values, and assumptions about perinatal loss in particular, and death and loss in general, colour this process? For example, is the process of meaning-making following perinatal death experientially different now than it was 20 or more years ago

when societal attitudes and support for perinatal loss were very different than they are today? How is the meaning-making process guided by individual characteristics such as spiritual beliefs, personality, past experiences with loss, and so on? After several years, have parents come to feel and think about the world differently than before their loss? Have their identities, values, and perspectives shifted or changed significantly because of their loss? Do they feel that they have changed because of their loss? How have they changed? These are some of the questions to which I searched for answers by listening to other bereaved parents' narratives of perinatal loss.

### 1.1 A Personal Touch

The second, but no less important, goal of this project was to evoke an empathic understanding of the experience of perinatal loss (Ellis, 2004). I attempted to move beyond an academic analysis of the experience of perinatal loss to reflecting "life as lived" (Ellis & Berger, 2003, p. 173) in order to add a level of emotional understanding that is not possible with traditional research methods. I drew from autoethnography and reflexive ethnography methods of writing qualitative research, which allowed for the incorporation of my personal experience into evocative renderings of the parents' narratives (e.g., Cherry, 1996; Ellis, 2004; Ellis & Berger, 2003; Ellis & Bochner, 1992; Kiesinger, 1995; Ronai, 1996; Tillmann-Healy & Kiesinger, 2001). Alternative forms of qualitative writing, like evocative narratives, employ writing techniques such as changing voice and tense, setting up scenes, writing in dialogue form – in short, using writing techniques to "tell a good story" that is true to participants' stories and compels readers to both know *and* feel the participants' experiences (Ellis, 2004; Kiesinger, 1995).

One benefit of this non-traditional, post-modern form of qualitative research is to allow readers to consider for themselves how my experiences and subjectivities inevitably influenced how I interpreted, understood, and portrayed the experiences of my participants. Researcher self-reflection or *reflexivity* is particularly important and useful when a researcher has had personal experience with the topic at hand as I have (Farnsworth, 1996; Kiesinger, 1995). My personal stories and reactions serve as an honest revelation of how I arrived at my interpretations of my participants' stories, allowing readers to judge for themselves how my personal experiences influenced my interpretation and presentation of others' experiences (Gilbert, 2001). Revealing aspects of my personal experience also serves as an additional source of data in this attempt to better understand the experience of perinatal loss.

### 1.2 Personal Assumptions

I come to this topic with some personal assumptions and expectations about the consequences of perinatal loss for families. For example, I believe that an attachment can form

at any stage of pregnancy whether an unborn baby<sup>3</sup> is wanted or not, and if an attachment has formed, some degree of grief is inevitable. I acknowledge the possibility that some parents may not view the loss as being as significant as others do, and that for some parents the grief process might be very short-lived or even non-existent. My presumption, however, is that for the majority of mothers and possibly many fathers, perinatal loss is similar, in many respects, to the loss of an older child. I do believe, however, that a perinatal loss brings with it some unique hurdles that are not present in the loss of an older child, and vice versa. Similarly, my position is that a perinatal loss presents different challenges to the grief process in some respects than does an earlier pregnancy loss (i.e., miscarriage, ectopic pregnancy). For this reason, I decided to focus solely on perinatal loss in this study, in an attempt to explore the hills and valleys unique to this type loss. As I journeyed through the interviews, analysis, and writing for this study, my personal subjectivities and assumptions inevitably coloured my perception of participants' stories. I attempted to maintain a conscious awareness of this whenever possible, in an effort to present my participants' stories in a manner that is faithful to *their* intended message in addition to my own (Parr, 1998).

### 1.3 Outline

In the chapter that follows, I briefly describe the historical context that led to the existing pregnancy and perinatal loss research, and then touch on the major findings and messages from this research. With this context in mind, I then explore the unique aspects of perinatal loss as compared to other losses, including the loss of an older child, to set the stage for a discussion of the types of obstacles parents face as they search for meaning in their loss. I follow this section with a consideration of some selected grief theories and how well they account for the unique problems of parental grief. I then discuss the concepts of meaning-making, trauma and the "assumptive world," the hurdles and supports that can influence the process of making sense of a loss, and the possibility of emerging from the trauma of grief as a transformed person. I follow this discussion with a consideration of how a qualitative, narrative approach helps to reach a better understanding of these phenomena, which may be an important part of a parent's lived experience of perinatal loss. In chapter 3 I discuss the methodology I used, including the issue of allowing a researcher's self into research and how

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<sup>3</sup> Other researchers studying perinatal loss have used neutral or formal terms such as "would-have-been parents" (Layne, 1996), "individual(s)" or "women/men" to refer to the bereaved parents, and "wished-for baby" or "foetus/embryo" for the babies lost during pregnancy (e.g., Lauterbach, 1993; Speckhard, 1997). Based on my own experience, and out of respect for the parents I interviewed, I followed the parents' lead in using the terms "parent," "mother" or "father" when referring to the bereaved individuals, and "baby" or "child" rather than "foetus".



doing so can lead to a rich, trustworthy, and valid study of human emotion and experience. The final 7 chapters contain the parents' stories, my interpretation, conclusions and recommendations.

## 2. RESEARCH CONTEXT

### 2.1 An Overview of Perinatal Loss Literature and Research

*As the third month after my baby's death approaches, I sit at my computer, doing a literature search on pregnancy loss, stillbirth, perinatal loss, miscarriage. My first search comes up with over 200 abstracts. "Wow," I think to myself, "that's a lot... probably all quantitative though." My suspicions are correct. My eyes scan the first few pages quickly, and I feel anger well up deep in my stomach, rising slowly to my chest. "They all focus on pathology, of course," I think, angrily: How many women develop depressive symptoms or anxiety, and how long does "normal" grief last? Women who are anxious or "depressed" longer than 6 months to one year are considered to have a chronic grief response. Some of the abstracts seem to contain a tone of surprise that so many women actually grieve after miscarriages and stillbirths. I read between the lines and find that others seem to be coming to the same intuitively obvious conclusion, but with a feeling of grim triumph rather than surprise, as if to say, "See! These parents DO grieve! Why did anyone ever suggest otherwise??"*

*As I scroll through the abstracts more slowly, I read about other studies that considered the psychological response of men to miscarriage and perinatal losses. "Well, at least they acknowledge that men might possibly feel something after such a loss!" My thoughts continue to carry a feeling of angry sorrow and bitterness. I am appalled that an experience such as the loss of a baby has been dealt with in such a superficial fashion, with psychometric measures and simplifying statistics. My experience cannot be summed up and packed neatly into a few words or phases on a rating scale. It doesn't make sense to me to rate the complexity of grief and its "duration" on dehumanising scales that try to determine how often you still think about your loss, and whether that is pathological or not. A few little numbers representing the answers to such questions do not tell me anything meaningful about the thoughts, feelings, and changes experienced by these parents. In my emotional state of mind, my only conclusion is that such research approaches try to force something that is so complex to fit neatly into simple but meaningless answers. I am even more convinced that I want to pursue a qualitative study that will reveal the full depth of the experience of perinatal loss, through the eyes of the real experts, the parents, rather than some 'objective' researcher.*

§

While the raw emotion of my early grief led me to feel angry and cynical about the quantitative research that has been done on miscarriage and perinatal loss, I eventually came to see that some of this research provided important validation of and information about these experiences. In some cases, the findings from quantitative studies were instrumental in urging health care providers to deal more sensitively with cases of miscarriage and perinatal loss. Other studies identified areas of concern that have been beneficially explored in further depth through more qualitatively oriented research. For example, the discovery that large numbers of women developed complicated bereavement symptoms prompted further studies that more deeply explored the unique hurdles faced by these mothers and their partners (e.g., DeFrain et al., 1990-1991; Gilbert & Smart, 1992).

This section provides a glimpse of the historical context that led to the existing perinatal loss research. It is followed by a cursory review of what is currently known about the psychological response to perinatal loss, based on quantitative and clinical research and theories, as well as some key qualitative studies of perinatal and pregnancy loss.

### *2.1.1 Historical Context*

Within the major industrialized nations of the world the rate of perinatal loss has been approximately 14-22 per 1000 live births since 1980, with the rate decreasing somewhat over time (Berman, 2001; Boyle, 1997; Centers for Disease Control, 2001). The causes of perinatal loss are many and varied, with the most common being chromosomal abnormalities and congenital anomalies (i.e., various birth defects), birth asphyxia and other respiratory conditions, cervical, cord, and placental problems, foetal malnutrition, and prematurity (Boyle, 1997; Berman, 2001). In the case of stillbirths alone, the cause of death is often undetermined (Cole, 1995).

Although it may seem intuitively obvious that parents grieve deeply for a baby who dies in the perinatal period, health and mental health professionals have only recently come to recognize the depth and intensity of this grief. Until approximately 1980<sup>4</sup> in the developed nations of the world, babies who died in the perinatal period were removed quickly from their parents' sight (mothers in particular), and speaking of the baby and its death thereafter was often taboo (Gilbert & Smart, 1992; Lewis & Page, 1978). The assumption made by both medical professionals and society in general was that bonding between parents and their baby did not begin until well after birth (Leon, 1990). Thus, it was assumed that preventing parents from seeing the baby would help in thwarting the development of an emotional attachment, thereby protecting parents from unnecessary pain and grief (Boyle, 1997; Gilbert & Smart, 1992).

Given this context, an important purpose of the psychiatric/medically-focused perinatal loss research has been to support the claims of early anecdotal reports that hospital practices needed to be improved and carried out with greater sensitivity to reduce the incidence of negative psychological outcomes in mothers. This scientifically-based justification for improved care of bereaved parents was necessary largely because of problems that arose as a result of the shift in the 20<sup>th</sup> century from medical care within homes to more scientifically/objectively-

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<sup>4</sup> Throughout this dissertation I have used 1980 as the dividing line to distinguish between the experience of parents whose losses occurred decades ago and those whose losses occurred more recently. I chose this date rather arbitrarily, as a representation of the approximate period when a more compassionate

based care within hospitals. The development of large-scale hospitals moved birth and death from the personal atmosphere of the home and placed them in the professional and emotionally distanced atmosphere of hospitals (Hutchins, 1986; Kennell & Klaus, 1976). For families facing perinatal bereavement prior to the 1980s, this translated into hospital personnel avoiding the emotional side of the death of a baby and focusing on the physical health of the mother. Often, mothers were quickly sedated after the baby's delivery or death. Decisions were left to husbands, who were strongly encouraged by hospital staff to exclude the mother from decisions such as burial and funeral arrangements (Lovell, 1983; Peppers & Knapp, 1980a). Women were generally not given the opportunity to see their dead or dying babies, and it was strongly recommended that they not see the babies if they expressed any interest in doing so. Even when physicians and nurses recognised the potential for grief on the part of perinatally-bereaved parents, they assumed that mothers would suffer less if they were prevented from having contact with the dead or dying infant. Berman (2001), an obstetrician trained in the United States during the 1970s, illustrated the common mentality instilled in doctors early in their training:

I was taught by respected and caring mentors that if a baby was stillborn or born with a serious, "unsightly" birth defect, the physician should attempt to protect the parents from the "shock" of seeing their dead child by covering it with a blanket, quickly removing it from the delivery area, and sending the body to the morgue to be buried in an unmarked grave. It was *thought* that this was helping the parents. We were unaware of the necessity of allowing them to bond, grieve, and have closure. (p. xvii)

In addition to this protective mentality, there was a strikingly widespread tendency for the medical profession to ignore or avoid the possibility that it was normal for the loss of a baby to elicit a grief response in parents (Boyle, 1997). For example, in 1976 Peppers and Knapp (1980a) interviewed and received letters from hundreds of women throughout the United States who had experienced perinatal loss. Many of these women reported dissatisfaction with the response of their nurses and physicians, who often exhibited insensitivity in their comments and discouraged women from displaying emotion or discussing their loss. For example, one woman described the response of a nurse after her baby died (Peppers & Knapp, 1980a):

One of the nurses, one that I thought was very good, asked me why I was crying. I said, "My baby has died!" She responded, "Well, you can have another baby. Your parents and husband are waiting for you. Keep a stiff upper lip, I don't want to see any crying." (p. 105)

More than 25 years later, with the beginnings of more sensitive care, the institutional nature of hospitals makes it almost inevitable that medical staff continue to be the authoritarian

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response to perinatal loss began to emerge within the medical establishment based on early research

gatekeepers who determine how long parents spend with their babies, and the quantity and quality of pictures taken. In most cases, parents are too shocked immediately after their loss to make well-informed choices, and therefore depend on the more clear-headed hospital staff to guide them through the necessary decisions. From her interviews with mothers and hospital staff in London, England, Lovell (1983) noted “the assumption of implicit authority” in the language used by staff. For example, staff talked about “*letting*” women see their babies, and a senior nurse commented that a woman “is even *allowed* to take a photo if she wants to” (Lovell, 1983, p. 756, emphasis in original). For many parents, this authoritarian stance induced them to be afraid to question hospital policy.

Lovell (1983) also found that as a general rule, health care workers (and society in general) considered early pregnancy losses to be less significant than later ones, and that late-pregnancy loss or neonatal deaths were not nearly as significant as the death of other loved ones. If the baby was physically deformed it was not considered by staff to be a “proper” baby, with the implication that it was “not worthy of mourning” (Lovell, 1983, p. 757). The language used within an early case-study report (Lewis & Page, 1978) illustrates the lack of value professionals placed on a baby who was stillborn pre-1980: “we asked them about the stillbirth...[the father] had not seen the stillbirth...They had given the stillborn a name...Like other dead children, stillbirths are idealised...” (p. 239). Rather than referring to the baby as a “stillborn baby” or simply “their baby,” the descriptive term for how these babies died became their identifying label. Assumptions such as this were communicated both implicitly and more explicitly and insensitively to parents. It was assumed that all parents were as horror-stricken by the emotional and visual images of these babies as were the professionals serving them. Later research proved otherwise.

### *2.1.2 What is known about perinatal loss?*

Within this historical context, clinicians, researchers, and perinatally-bereaved parents began in the 1970s and early 1980s to work toward establishing that perinatal loss is indeed a significant loss that must be acknowledged (e.g., Borg & Lasker, 1981; Davidson, 1977; Lewis & Page, 1978; Peppers & Knapp, 1980a). Many of these early studies, case reports, and descriptive accounts focused on describing the acute grief period and provided evidence that parents, particularly mothers, did in fact grieve the loss of their babies. These early works also pointed out that the common medical and funerary practices for stillbirth and early neonatal death were insensitive, often impeding mothers’ ability to grieve normally and having negative

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studies demonstrating the significance of this form of loss.

repercussions on the family as a whole (Kirkley-Best & Kellner, 1982; Kirkley-Best & Van Devere, 1986; Peppers & Knapp, 1980a).

The majority of perinatal loss research to date has approached the topic from a traditional positivist medical model, with all of the assumptions that go along with such a model. The types of questions that follow from a medical model are generally consistent with viewing the grief response as analogous to a disease. Thus, research questions have to do with topics such as prevalence of abnormal grief responses, delineating the underlying psychological, biological, and social factors associated with the observed grief response, and so on. A quick scan of the answers to such questions allows us to hear the voices of researchers and clinicians telling us about perinatal loss as seen through the lens of a traditional research model:

1. What is the typical psychological response, including intensity and duration of grief? Is a perinatal death a significant loss for parents, one that follows the phases of grief that are seen in other significant losses (loss of a spouse, a parent, an older child)? Are there parents who do not grieve (i.e., not a significant loss)?

Leon (1990) stated that our understanding of the typical outcome after pregnancy and perinatal loss is incomplete, being based, for the most part, on poorly designed studies<sup>5</sup>. Because of this, the incidence of poor psychological outcomes is unclear. That being said, the general consensus has been that for the majority of women (the data being less clear for men), there is a 6-12 month recovery period, with grief increasing somewhat around the 1-year anniversary and tapering off thereafter (Janssen, Cuisinier, Hoogduin, & de-Graauw, 1996b; Leon, 1990). However, given the lack of data concerning outcomes beyond one or two years, others have argued that it is premature to speak to “long-term” outcome (Boyle, 1997; Lin & Lasker, 1996; Zeanah, 1989).

The symptoms of grief experienced by perinatally-bereaved parents, as well as the phases of grief, appear to be generally similar to those seen in other forms of bereavement (Boyle, 1997). However, Lin and Lasker (1996) found that parents who were followed over the course of two years showed patterns of change in grief that were different from those usually cited in the bereavement literature. For example, some who were experiencing what would have been labelled “chronic grief” one year after their loss were recovering well in the subsequent year. On the other hand, another group of parents experienced more grief symptoms two years

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<sup>5</sup> Leon suggested that *quantitative* researchers strive toward the ideal study: longitudinal, prospective studies with a non-bereaved group for comparison, long-term follow-up, using a combination of objective scales (e.g., depression) and clinical interviews which could assess a range of risk and protective variables on both an intrapsychic and interpersonal level.

after their loss than at the one-year anniversary. These findings were not expected based on the “normal” grief model from which most theories are derived (based largely on spousal bereavement studies). Lin and Lasker pointed out the importance of following parents beyond the two-year mark, so that these variable patterns of the course of grief are not missed.

2. What are the risk factors for complicated bereavement? What proportion of parents display complicated bereavement, including rates of anxiety and depression at various times following the loss?

Early studies and case reports were consistent in suggesting that a lack of acknowledgement of perinatal loss, including the common practice of encouraging parents to forget their loss rather than grieve it, led to serious psychological problems for many mothers (e.g., Lewis & Page, 1978; Peppers & Knapp, 1980a; Phipps, 1981). For example, Lewis and Page (1978) described a young mother who was unable to care for her 3½-month-old daughter because of unresolved grief over a previous stillborn baby. Other studies revealed severe cases of psychological problems – anxiety attacks, phobias, severe depression, obsessions, and psychotic reactions (Kirkley-Best & Kellner, 1982). Later studies confirmed that poor social support following a perinatal loss is a significant risk factor for complicated bereavement patterns (see Zeanah, 1989 for a review).

Janssen and colleagues (1997) identified other key risk factors for complicated bereavement, including a relatively long pre-loss pregnancy, more pre-loss psychiatric symptoms, and the absence of living children. Another potential risk factor for chronic grief is death of the baby as a result of congenital anomalies. One study (Hunfeld, Wladimiroff, & Passchier, 1997) found that 11 of 29 women (38%) displayed a clinically significant level of psychological distress up to four years after the loss of a baby who had birth defects incompatible with life outside the womb. Although the authors did not speculate about this finding, they did note that one-quarter of the women continued to be distressed over intrusive images of their baby, suggesting the event was traumatic for them (some of the women were “haunted with doubts about their infant’s malformation”; p. 90).

Boyle and colleagues (1996) provided strong evidence that those women who continued to report high levels of anxiety and depression eight months after the death of their babies were most likely to continue being distressed at the 30-month mark. This enduring distress beyond the 8<sup>th</sup> month after the loss was seen only in a small number of women (roughly 10%). Similarly, Janssen and colleagues (1996a) cautioned that although early studies reported large numbers of perinatally-bereaved women exhibiting pathological grief, a critical look at such studies suggests that the definition of “pathological” was based on the assumption that grief lasting more



than 8 months to 1 year was abnormal. As Zeanah (1989) put it, these early studies equated intense grief with “pathological” (and, conversely, minimal or absent grief has also been labelled pathological). Depressive symptoms were often taken to indicate clinical depression rather than a natural grief reaction (Zeanah, 1989). More recent and better-designed studies with a more realistic definition of pathological have indicated that the vast majority of women are able to “recover” (accept the loss and resume day-to-day functioning) from pregnancy loss within one to two years. In reviewing studies of pathological grief, Janssen and colleagues (1996a) concluded that: psychological distress is common (and normal) in the first six months following a loss; 10-15% of women develop a clinically significant psychiatric problem (e.g., mood disorder, somatic complaints, anxiety disorder, impaired functioning, post-traumatic stress disorder, obsessive symptoms) during the first two years following a loss, with less than 10% seeking psychiatric help; and one in five women is unable to accept the loss as long as two years post-loss. The authors cautioned further that more longitudinal studies (i.e., following women for more than 2-4 years) are needed before conclusions can be drawn about long-term grief after perinatal loss.

3. Is there a quantitative (e.g., grief intensity and duration) or qualitative difference in the grief response following the various types of pregnancy and infant loss (miscarriage, stillbirth, neonatal death, Sudden Infant Death Syndrome (SIDS))?

Most studies, particularly those conducted since 1980, combine the various types of pregnancy and infant loss, regardless of whether their research questions have to do with comparing them. Early studies provided inconsistent results on this question. For example, Peppers and Knapp (1980b) found a similar grief response in mothers losing babies through miscarriage, stillbirth, and neonatal death (as measured by grief response and current symptoms rating scales). In contrast, others have found what has generally been an assumption in North American society: the longer the gestational period (or time with a live infant), the more intense the grief (e.g., Lasker & Toedter, 1991; Lin & Lasker, 1996). Looking only at women who had miscarriages, Madden (1994) found a wide variety of reactions to the loss, from mild sadness that resolved quickly, to being more deeply affected for a much longer period of time. Dyregrov and Matthiesen (1987) found greater psychological distress, including anxiety and intrusive thoughts, among parents who had a baby die of SIDS than those experiencing stillbirths or neonatal deaths. They also found a clear relationship between how long the baby lived and parents' long-term adaptation, in that parents whose babies died soon after birth (or in utero) had fewer long-term adaptation problems. In looking at this issue more closely, it is now generally accepted that the important factor in determining grief intensity is the degree of



attachment that parents feel toward their unborn child, rather than gestational age or the length of life of an infant (Madden, 1994; Peppers & Knapp, 1980b).

To make the picture more complicated yet, Theut and colleagues (1990) found that parents' grief responses to early losses versus later losses differ most in terms of the subsequent pregnancy. That is, parents experiencing early losses showed decreased grief scores as soon as a subsequent child was born, whereas parents having later losses continued to have higher grief scores until 16 months after a subsequent child was born. The authors suggested that the difference may be related to the often greater intensity of physical and emotional attachment in late pregnancy, as well as the additional bonding that takes place when a parent sees and holds their stillborn or newborn child. Based on results like these, Zeanah (1989) pointed to the importance of further exploration of the differences in the grief process for the different types of pregnancy and perinatal loss. Extending this argument further, it could be said that studying the different types of loss separately is important, given these subtle but clear differences.

#### 4. Is the grief of fathers less intense or different than that of mothers?

As implied above, the majority of miscarriage and perinatal loss studies have focused on the mother's response. Generally speaking, studies have found that in comparison to mothers, a father's grief is less intense and long lasting and he tends to experience less guilt and depression (Leon, 1990). There is also some evidence of gender differences in coping strategies used after pregnancy loss, with men worrying or ignoring the situation more, and women seeking spiritual support or support from others who have experienced the same type of loss (McGreal, Evans, & Burrows, 1997). This is consistent with the gender differences in styles of grieving seen with other forms of bereavement (Lund, 2001; Martin & Doka, 2000; Rando, 1986). Differences in grief intensity between men and women are found particularly in miscarriage studies, with men grieving less intensely and enduringly, crying less, and feeling less need to talk about the loss (e.g., Beutel, Willner, Deckard, Von-Rad, & Weiner, 1996). Men are also less likely to respond with a depressive reaction to miscarriage (Beutel et al, 1996). When considering men's reactions across the different types of losses, there is some evidence that men have a less intense and long-lasting grief response to earlier gestational losses than to late losses (Lasker & Toedter, 1991). These results are consistent with the suggestion that men do not bond to their unborn child as soon, or in the same way, as do mothers (Leon, 1990), although this is an issue that requires more study. The lack of information about fathers' grief is consistent with the generally poor level of support and recognition they receive for their loss (Lasker & Toedter, 1991).

5. What influence does a perinatal loss have on various life domains (subsequent pregnancies, marital relationship, family relationships, etc.)?

What is clearer than the data on a father's grief is that the father's emotional response to perinatal loss can significantly influence his partner's course of bereavement (Leon, 1990). When the grief of partners is very incongruent (as it tends to be, especially with early losses), relationship tensions are likely to arise (Gilbert & Smart, 1992). As well, even when men grieve as deeply as their partners, their different style of grieving (a tendency to suppress their grief and grieve more privately) can be construed by their partners as being an indication that they are not as deeply wounded by the loss (Leon, 1990). Studies have found that lack of support from the male partner is a risk factor for more intense and complicated grief on the part of the mother (e.g., Dyregrov & Matthiesen, 1987). Whether the reverse is true has not been investigated empirically. Some studies have suggested that marital problems are highly likely after a perinatal loss, as they are after the death of an older child (e.g., Rando, 1986; Wing, Burge-Callaway, Clance, & Armistead, 2001). While it is clear that strain is placed on a marriage after a perinatal loss, the majority of relationships appear to pull through, with some families even reporting improved relationships (Gilbert & Smart, 1992; Zeanah, 1989).

The psychological impact of a perinatal loss on subsequent childbearing has been well documented, but only a few studies have focused on this issue. Women who become pregnant subsequent to a perinatal loss have been found to have elevated anxiety levels, which appeared to be specific to the subsequent pregnancy rather than generalised anxiety (Theut, Pedersen, Zaslow, & Rabinovich, 1988). Women who have had previous losses may be more likely to think of their baby as a person, rather than a foetus, early in pregnancy (Statham & Green, 1994). Prior to the recognition that parents must grieve a perinatal loss, common practice in the medical profession was to encourage parents to have another baby as soon as it was physically advisable (Kirkley-Best & van Devere, 1986). It has since been recognised, however, that parents need time to grieve their loss, rather than trying to replace the baby who died (Leon, 1990). Some studies have indicated that parents, particularly mothers, feel a strong compulsion to get pregnant again very soon after a perinatal loss (Zeanah, 1989). The danger in this is that the often inevitable grief will be delayed and will surface again sometime after the subsequent child is born. As well, both over-protectiveness and replacement feelings toward the subsequent child have been reported to occur in some families (Zeanah, 1989). The effect of these unresolved grief issues on the subsequent child, as well as children born before the loss, can be quite negative (Speckhard, 1997; Zeanah, 1989) – such as an increased risk of mother-child

attachment disturbances in children born subsequent to the perinatal loss (Heller & Zeanah, 1999).

In summary, early literature and studies worked toward dispelling the myth that grief would be prevented if parents were shielded from seeing their babies and discouraged from engaging in mourning rituals. This research also demonstrated the high rates of psychological morbidity and family functioning problems following miscarriage and perinatal loss, which resulted in the recognition of the need for improved care practices and efforts to help parents face and cope with their grief, rather than avoiding it. From these quantitative and descriptive studies, important recommendations were made for more humane acute hospital care and treatment programs for these parents (e.g., Boath, Barnett, Britto, Pryce, & Cox, 1995; Borg & Lasker, 1981; Moscarello, 1989; Thomas, 1995).

There is no doubt that such studies are valuable and important. However, if exploring the experience of perinatal loss in greater depth is the goal, these studies do not suffice. Mauthner (1999), in studying postpartum depression after a normal pregnancy, provided a helpful critique of the difference between adopting a medical model from the post-positivist tradition versus a more qualitatively-oriented social scientist approach to studying human experiences. As we have seen in this section, viewing human experiences from a medical model within this tradition leads to questions about prevalence (e.g., of depression, anxiety), underlying psychological, biological, and social variables that correlate with the “problem,” and so on. On the other hand, approaching such experiences from a qualitative research framework allows for asking questions that are often more meaningful to the individuals concerned. A post-positivist medical model tends to devalue an individual’s own subjective experience, assuming it is not trustworthy and that the average person is not capable of insights into his/her own experience. A qualitative approach invites these “subjective” voices into the data, and may even allow participants to determine the direction that research questions take.

### *2.1.3 Listening to Parents’ Voices*

What wisdom have bereaved parents shared that helps us better understand the lived experience of perinatal loss? What stories have they told that provide different insights than traditional researchers’ “stories”?

Then, without warning, I am seeing not Jacob [her second baby] but our first son. For the first time, I truly understand that he was a baby, not the dream of one. I realize that he was solid, that he must have looked very much like Jacob, that he was his brother. He is born, for me, at this instant. My heart pinches so that I lean forward and put my face in my hands. “What’s wrong?” says Peter [her husband]. “What did he look like?” I ask through my hands. He knows what I mean. He doesn’t answer for a long time. My eyes are closed, but I’m seeing the baby that someone must have held, that Peter saw

emerging from my body. When he speaks, his voice has to overcome an inertia of pain, and begs my forgiveness for what he has seen and I have not. "He looked more like me..." My grief, which I thought had been healed, doused and put to rest, seizes me. Tears come from a source that I thought had been exhausted. (Powning, 1999, p. 193)

This excerpt is from the book *Shadow Child* by author Beth Powning, the story of one woman's experience of learning to grieve for her stillborn son. Powning's son was born in 1975, prior to the growing awareness that perinatal loss is a significant loss. Like so many other parents during and prior to that period, she did not see or hold her stillborn son or officially give him a name. It took her until 1993, almost 20 years, to finally recognize that she had not allowed herself to grieve for her son. During those years she managed to function well in her daily life; her description of their lives leads one to conclude that she was a good mother and had a good relationship with her husband. She did not suffer serious depression, anxiety, or other psychological problems during those years. Her response once she realized she had not allowed herself to grieve for her son would not be considered pathological. Yet, this brief excerpt reveals the intense pain that she and her husband endured, largely unsupported and unacknowledged by themselves and those around them.

It is personal stories like these that, for me, reveal the depth and diversity of the lived experience of perinatal loss. A few qualitative studies have looked to stories like these, told by parents in interviews, to better understand perinatal loss from a different perspective, a different angle, with a different lens.

Qualitative researchers have taken a variety of approaches to the study of perinatal loss, including grounded theory and thematic analysis, phenomenology, and a feminist perspective (e.g., DeFrain et al., 1990-1991; Gilbert & Smart, 1992; Lauterbach, 1993; Layne, 1996, 2003; Rosenblatt & Burns, 1986). From these studies we have learned that parents describe their grief much the same as do parents losing older children: "I thought I'd die of a broken heart"; "It was like someone took a part of my very soul" (Gilbert & Smart, 1992, p. 29). They remember the events surrounding their loss in minute detail (Rosenblatt, 1986). They are left reeling from the disruption of their assumptions of how the world works – that they are not invulnerable to harm after all, that the world does not work on a system of "fairness," and so on (Gilbert & Smart, 1992). Layne (1996) found that parents' writings of perinatal loss contain a number of ironies as an important recurring theme. Mothers lament about things not turning out as they are supposed to, as they were expected to, as they should have. Some parents are stung by reality, realising that the common belief that pregnancy automatically results in a joyous event is a myth. Parents' poetry contains themes of the cruel ironies of beautiful nature juxtaposed on the details of the loss - for example, the beauty and newness of springtime coinciding with a baby dying,

shattering previous assumptions such as spring as a metaphor for new life, birth, joy, and happiness (Layne, 1996). At the same time, Layne found that nature does play a role as a “spiritually healing force” for many bereaved parents, reflected in their references to nature using terms implying comfort and healing (p. 140).

In trying to establish a new sense of order, parents search for meaning in their loss (Gilbert & Smart, 1992). They gather information on perinatal loss, trying to determine where they are in the grief process, and how they compare to others who have lost children (Gilbert & Smart, 1992). They look for answers to why their child died, needing to know medical causes, who was at fault (many blame themselves), and whether it could have been prevented. Comparing themselves to others serves as a means of comforting themselves (e.g., “it would have been worse if...”); but if others they talk to make similar comparisons, many parents are hurt and angered, feeling as though their loss is being minimised (e.g., “well, at least you didn’t get to know him”) (Gilbert & Smart, 1992). Many parents’ spiritual faith becomes strengthened; others question their former spiritual beliefs, particularly if they believed in a God who is in control of all things (DeFrain et al., 1990-1991). Some parents comment on the surreal nature of the death of their babies – one minute they were preparing for a new family member, the next they were being told he/she was dead or would die soon (DeFrain, 1991). Mothers who have had a stillborn baby must make sense of the paradox of birth coinciding with death<sup>6</sup>. Some question their sanity, particularly when they have been unable to talk openly or reflect on their feelings of grief because of the historical taboo that was placed on talking about perinatal loss (DeFrain et al., 1990-1991).

Eventually, the cruel irony is “vanquished and the myths restored” (Layne, 1996, p. 143). For some parents, religion and spirituality serve as a framework for making sense of the discrepancies between common societal assumptions and the harshness of their reality. For others, finding ways to memorialise their child, particularly through helping others, aids in making sense of the loss (Gilbert & Smart, 1992). Finding and making meaning in the loss often leads to some form of grief resolution for some parents; still, feelings of grief continue to recur throughout many parents’ lifetimes (Gilbert & Smart, 1992; DeFrain et al., 1990-1991).

Parents describe grief resolution following a perinatal loss as an ongoing process that does not really end, even though they are once again able to function and have renewed hope for the future. DeFrain and colleagues (1990-1991) reported that after communicating with more

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<sup>6</sup> Powning (1999) expressed this experience poignantly: “This small, sturdy body has taken me to places I never imagined, places where [my husband] couldn’t follow. My soul has been driftwood in its sea. I’ve carried life in my womb, and I’ve carried death. I’ve given birth to both.” (p. 6-7)

than 700 parents, not one felt they had returned to “normal” after their loss. Instead, every aspect of individual and family life is permanently changed to some degree, in both positive and negative ways. Individuals report feeling they have changed: for instance, they feel they are better parents because of the death of their baby, or they become more empathetic to other bereaved persons (Boyle, 1997; DeFrain et al., 1990-1991; DeFrain, 1991). Many couples are able to manoeuvre their way through the tangle of destabilising tensions and conflicts that they experience as each tries to grieve separately yet support one another. However, just as the individual emerges in a transformed way, so too does the relationship in many cases, with new skills for relating to one another and greater sensitivity and acceptance of one another’s differences and needs (Gilbert & Smart, 1992).

With this brief glimpse of some of the conclusions drawn from the words of perinatally bereaved parents, it is clear that perinatal loss brings with it both unbearable hurdles and positive changes. Although some of these aspects are common to other forms of bereavement, the nature of perinatal loss makes consideration of its unique presentation particularly important.

## 2.2 Unique Issues of Perinatal Loss

*One thing that the perinatal loss literature talks about is that such losses are often about the various things besides the individual baby that was lost. That is, when older loved-ones die, many losses are grieved (e.g., identity as a spouse, etc.), but the primary loss is of that person, and learning to live without him/her. What is said about pregnancy/perinatal loss is that the primary thing grieved is not the baby itself, since it wasn’t known well as an individual with a specific personality. Instead, they say the focus of the grief is on the many other losses such as lost identity as a parent to this child, lost innocence, narcissistic pain, etc. Is this true in my experience? Often I have grieved over the injustice of it all – self-pitying thoughts of “why me,” particularly around the issue of not knowing if it will happen again in a subsequent pregnancy, and the stress of that. I have also grieved for the delay in having children – being deprived of that, having no control over making it happen sooner. But I have grieved primarily for the loss of Jacob. I wonder what he would have been like, I grieve because I didn’t get to know him, I miss him every time I see a child who is about the age he would be now, and I grieve over the fact that I can’t be a mother to him, not just to any child. I grieve because he does not need me now, and I’m not sure what to do with my instincts to be a mother. So, yes, I do grieve for Jacob, the specific baby boy that I gave birth to... (journal entry, February 2001)*

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When compared to other forms of bereavement, parents experiencing perinatal loss face many of the same obstacles in their grief as do parents bereaved of older children. Braun and Berg (1994) identified a number of issues that make parental bereavement unique in comparison to other types of losses. First, because of the unique dynamics of the parent-child relationship, in losing a child a parent also loses a part of themselves. From the time that parents begin to prepare for their unborn child to enter the world, they form a narcissistic bond to their child – one that remains to some degree even as the child develops his/her own identity (Leon,



1990). When the child dies, this narcissistic loss is a part of the unbearable grief. As well, in Western cultures the parent-child relationship is a special one in which parents typically invest their hopes, dreams, and expectations in the lives of their children. In this way, a part of the parent's hope for the future is lost when a child dies, and their wishes and fantasies for their child's future need to be grieved along with all of the other losses involved.

With a loss of a baby or an older child, parents also lose their identity as protectors of and providers for this child (Braun & Berg, 1994). Many parents feel a sense of failure because they were unable to protect their child from death. Additionally, North Americans tend to view the death of a child as unnatural<sup>7</sup>, a paradox – death as bad, frightening, a punishment, and childhood as goodness, happiness, and innocence. The death of a child is therefore particularly unexpected and goes against society's assumptions about how the world works. Some parents search for reasons to blame themselves, since their previous assumptions about the world led them to believe they had control over what happens; parents who carry such assumptions often feel that they must have done something wrong to deserve losing their child. Finally, the death of a child is often the first experience with death and grief for many parents, particularly when a baby or very young child dies. For these parents, the death of their child might be their first loss of innocence about the lack of control one has over many of life's events. They will have had less life experience, and know less what to expect about the grief process.

What makes a parent's grief unique, then, is that "for many parents an entire collection of assumptions about life are called into question" (Braun & Berg, p. 125). In many respects, a parent's perceived reality is called into question with the death of their child. These aspects of parental grief are believed to be a part of perinatal loss as well, but there are other unique characteristics, the very nature of perinatal loss and societal assumptions about it, that make the search for meaning and the resolution of grief different in some ways from the loss of an older child (Robinson, Baker, & Nackerud, 1999). These unique hurdles will be explored below: the psychology of pregnancy; the multiple losses of perinatal death; prenatal attachment issues; the traumatic nature of perinatal loss (Speckhard, 1997); and the socially "disenfranchised" nature of this type of loss (Doka, 1989, 2002).

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<sup>7</sup> Note that the death of older infants and children is considered unnatural and uncommon in today's society, but that at one time in history, pregnancy and infant losses were essentially expected (i.e., in the early 20<sup>th</sup> century and earlier, before medical advances reduced the infant and child mortality rates) (Layne, 2003). Miscarriages are still, in the present day, a realistic possibility that is anticipated by most expectant parents, making the "unnaturalness" argument not applicable in such cases. With increasing medical advances in saving premature babies at earlier gestational stages, later pregnancy losses and neonatal deaths are more likely to be experienced by parents in the present day as "unnatural" (Layne, 2003).

### *2.2.1 The Psychology of Pregnancy*

In considering the unique impact of perinatal loss on parents, it is useful to first consider the psychological aspects of pregnancy, the context from which perinatal death emerges. Leon (1990) provided a psychodynamic view of pregnancy, one of the only existing comprehensive treatments of the psychology of pregnancy in the context of perinatal loss. I will therefore draw heavily on Leon's work in this section.

Particularly for first-time parents, pregnancy can be considered a developmental stage, a transition point into a new phase of adult development – parenthood. With most developmental transition points there comes some degree of psychological disequilibrium. A whole constellation of identity issues, unresolved conflicts, past relationship problems with one's own parents – all of these can be stirred up for parents-to-be during pregnancy as they prepare for parenthood. The parent-to-be is preparing for both positive changes as well as losses which are often not acknowledged for fear of appearing to reject one's unborn child (e.g., loss of status as a non-parent, loss of income, loss of freedom) (Nicolson, 1999). Parkes (1993) termed such transition points "psychosocial transitions". These can include both positive and negative life events, such as pregnancy, marriage, and the loss of a significant loved one. These events are always life changing ones; they take place over a relatively short period of time so there is little time to prepare psychologically; and they prompt people to rethink their assumptions about the world (Parkes, 1993). In the case of perinatal loss, as parents are in the process of adapting psychologically to the idea of becoming parents (or expanding their family), they are suddenly and often unexpectedly thrust into another psychosocial transition, losing their child. The psychological shock and upheaval, above and beyond grief, can be intense.

In addition to being a developmental stage that must be worked through psychologically, pregnancy is also a time when many parents develop powerful fantasies of their unborn child's attributes (Condon, 1986; Leon, 1990). Leon pointed out that some parents, particularly mothers, develop such a strong conception of their infant's personality before birth that they continue to be influenced by those prenatal fantasies 6 months after birth. Thus, long before birth, many parents picture their child as a "real person" with unique characteristics. Leon took a psychoanalytic perspective in suggesting that a mother also integrates unconscious aspects of herself in her conception of her unborn child's personality. A mother's fantasies and images of her child can be a composite of her own psychological history and unconscious conflicts, and images of the father as well. This can influence a mother's relationship with her child after birth, or in the case of perinatal loss, can lead to feelings of intense guilt over ambivalence felt toward the baby prenatally.



Another realm of pregnancy that Leon (1990) explored is the self-enhancement experienced by parents when they conceive a child. Creating a child can be viewed as a way of making oneself immortal – both by passing on one’s genes, and living on through one’s children and grandchildren. An unborn child is also a psychological extension of a parent’s self – a narcissistic identification, and an experiencing of the unborn child as a part of oneself in addition to being a separate being of its own. The pregnancy can serve also as a way of boosting a parent’s self esteem, being a part of the miraculous production of new life. A pregnancy can be highly gratifying on a narcissistic level, for both parents. They often fantasise about the perfection of the child they have created, forming an idealised image that adds to their feelings of having done something extraordinary in conceiving their child (Leon, 1990).

An important part of pregnancy from the viewpoint of perinatal loss is, then, the narcissistic relationship with which parents greet their child into the world (Leon, 1990; 1996). The baby has been experienced as a part of the mother’s self, both physically and psychologically. The same can be said for the father to some degree, although the mother clearly has a more intense physical sense of the child being a part of her (which can influence the level and quality of attachment felt by each parent). The process of relating to the baby on a more separate-being level begins toward the end of pregnancy, but the narcissistic bond remains for some time after birth.

### *2.2.2 The Multiple Losses of Perinatal Death*

Given the psychological context of pregnancy, a perinatal death represents multiple losses that are somewhat unique to this type of loss. Leon (1990) pointed out the “shocking coincidence of pregnancy, the process of giving life, with death,” and how this evokes human mortality in a way that perhaps no other losses can (p. 42). Leon emphasised the narcissistic pain involved in a perinatal loss, which he held to be more significant than the sense of object loss (loss of a specific person). The narcissistic pleasure that parents felt during pregnancy turns to narcissistic pain, resulting in decreased self-worth and self-esteem, particularly for the mother, for whom the baby was also a physical part of herself. For the mother, a literal part of herself dies. The mother feels a sense of failure and guilt, having been unable to save her baby from death despite their intimate physical connection. As Leon noted, an important part of the grief of perinatal loss is the required grappling with this self-blame.

Mourning the object loss, the sense of the baby being a separate individual from the parents, is difficult with perinatal loss because the “object” was known for such a short period of time (Leon, 1990). The process of the baby establishing its own identity is cut short by the death, so it takes on/remains as being known by a mixture of identities – its own beginning separate

identity, its mother's, father's, and the history of its parents' relationships. The baby's individuality at such an early stage is intimately woven together with its parents' prenatal fantasies of its personality (Leon, 1990; Robinson et al., 1999). In many respects, it is these wishes and fantasies that must be mourned, more so than memories of the baby's individuality.

With little tangible evidence of the child's existence, the grieving process can be exceedingly difficult after a perinatal loss (Leon, 1990). In comparison to the loss of an older child, Leon suggested that grief of perinatal loss is usually not as severe. He does note, however, that the memories parents of older children have are an important outlet which, albeit painful, help in the mourning process. This is an outlet that is not available to parents having a perinatal loss. With other losses, the mourning is retrospective – a remembrance and longing for a person in one's past. Perinatal loss involves a prospective grief – mourning wishes, hopes, and fantasies about what almost was, but now, will never be (Leon, 1990).

Like parents losing an older child, parents whose baby dies experience a loss of parenthood, and, for those without other children, an uncertainty over their own identity as parents (Lovell, 1983). Unlike the loss of an older child, these parents face uncertainty over whether they could ever have been considered parents – their only experience of “parenting” a child was prenatally and perhaps for a brief time postnatally. Thus, they question their membership in the “parenthood” group, taking their cue from the response of society to their loss (Lovell, 1983). Despite having no baby to parent, mothers continue to experience an intense need to nurture and have physical contact with their babies, an instinctual frustration that must be coped with after the baby's death. This intense yearning to nurture one's baby appears to run deep both physically and emotionally; many mothers report a physical ache in their arms after a baby dies, and some awaken at night imagining that they heard their baby crying (Condon, 1986). Although this instinct to nurture is not as intense with fathers, both parents lose the opportunity for narcissistic pleasure in their maternity/paternity (Leon, 1990).

### *2.2.3 Prenatal Attachment*

It is generally accepted that the majority of individuals experience a perinatal death as a significant loss that needs to be grieved like any other death of a loved one. However, since the inception of research showing that many parents grieve deeply after a miscarriage or perinatal loss, Madden (1994) argued that the attitude toward these losses has shifted from one extreme to the other. That is, we have gone from avoiding and ignoring such losses to assuming that *everyone* who has any type of pregnancy loss experiences profound grief. Madden's study of women who had miscarriages found that the women's reactions varied much more than expected based on other research. Some women grieved very deeply and wanted their loss to

be recognised as being significant, while others were much less distressed and reported coming to terms with their loss very quickly (within less than four months). Madden cited the level of prenatal attachment as a significant factor in determining how emotionally distressed women were after the miscarriage.

Prenatal attachment, then, is an important factor in determining a parent's emotional response to a miscarriage or perinatal death. For many parents, forming an attachment to their baby begins well before birth, and in some cases, even before conception. For example, the desire to have one's own biological child while being faced with infertility can result in a very real experience of loss and grief for some parents (Speckhard, 1997). Robinson and colleagues (1999) highlighted the increasing evidence that attachment begins long before birth. They cited Peppers and Knapp (1980a) who proposed nine events that contribute to attachment before and shortly after birth: planning the pregnancy; confirming the pregnancy; accepting the pregnancy; feeling foetal movements ("quickening"); accepting the foetus as an individual; giving birth; seeing the baby; touching the baby; and giving care to the baby. Thus, maternal attachment (and paternal attachment to some degree) consists of tangible events such as foetal movement, but other more subtle aspects as well, including preparation and adjustment to the pregnancy and the idea of being a mother to this child; degree of investment in the pregnancy; fantasising about this child and its role in the family; and imagining how her life and family life will be changed by a baby. The general consensus is that these elements of attachment, rather than simply the length of pregnancy, must be considered in perinatal loss. Although later losses generally result in more intense and longer lasting grief, gestation length alone is not necessarily an indicator of the degree of attachment, as early studies suggested. Some parents become very strongly attached and decisively happy about their pregnancies in the first trimester, prior to noticeable foetal movements, and they grieve intensely and for a long duration, just as do parents having late losses (Leon, 1990). Others do not form these bonds until the baby becomes more visibly apparent later in pregnancy (Madden, 1994; Robinson, Baker & Nackerud, 1999). In essence, each parent experiencing a perinatal loss can react very differently depending on their definition of their own experience, the meaning they have ascribed to their pregnancy and their loss (e.g., "My child died" or "This was a sad and disappointing experience, but we can try again") (Moulder, 1994).

In addition to the intrinsic elements of pregnancy, a number of other factors appear to have some influence over the development of prenatal attachment. For example, some researchers have pointed to the influence of ultrasound and other reproductive technologies that have become common in the past two decades. Ultrasound imaging has allowed parents to hear

their baby's heartbeat early in the first trimester, as well as view images of their baby moving in utero. The impact of such early "contact" on a parent's feelings of attachment for their unborn child is beginning to be recognised (Robinson, Baker, & Nackerud, 1999). As well, with modern medicine helping to reduce the infant mortality rate in the past century, an unspoken assumption has developed in western society - that pregnancies that make it past the first trimester will end successfully. This assumption has led many parents to be willing to form bonds with their unborn children at earlier and earlier stages of pregnancy (Malacrida, 1999). In conjunction with this change, the widespread acceptance and availability of birth control measures some 50 years ago translated into couples waiting longer to have children and, presumably, being less ambivalent about having children once the decision is made. Furthermore, society has come to accept the myth that the success of pregnancy is under the woman's control: she can decide to allow it to continue or not, a healthy lifestyle and eating habits can help to ensure a successful outcome, and medical miracles, such as the ability to save extremely premature babies, will do the rest. The implication, which is usually accepted by women experiencing a perinatal loss, is that a pregnancy ends because of something the woman did wrong (Malacrida, 1999). Malacrida suggested that these beliefs are so embedded in our society that they are apparent within larger institutional practices as well.

Regardless of whether a pregnancy is planned and desired or not, there is often ambivalence in the prenatal attachment process (Speckhard, 1997). Some parents consciously resist attaching to the unborn child, citing fear of loss, especially if previous losses have occurred. For some, a certain degree of attachment feelings can develop even if the choice is made to terminate the pregnancy (Speckhard, 1997; Speckhard & Rue, 1992). Ambivalence in the meanings that parents assign to the pregnancy is common, even when a child is desperately wanted. For example, parents may have negative feelings such as viewing the unborn child as a burden that will change life for the negative, combined with the positive feelings of attachment or affection. This almost universal ambivalence in pregnancy helps explain the sometimes traumatizing effect of terminating an unwanted pregnancy (Speckhard, 1997; Speckhard & Rue, 1992). Ambivalence toward the unborn baby can be assigned in a retrospective way following the loss, often in the form of guilt, with mothers wondering if their ambivalence was responsible for the loss. Speckhard (1997) also noted that not all attachments and assignments of meaning in pregnancy are healthy. For example, during pregnancy some parents revisit their attachment experience with their own parents. If their relationship involved an insecure attachment, they may look to the expected child for what they did not have with their own parents in terms of stability and nurturance, attempting to overcome past attachment failures through their unborn

child. Alternatively, men and women expecting a child may not feel adequately equipped to be parents because of a poor relationship with their own parents. Scenarios such as these will complicate the meanings assigned to a pregnancy loss, and thereby make the grief process more problematic.

#### 2.2.4 Trauma of Pregnancy Loss

*While at the hospital it was decided that I needed to have an x-ray [for a leg injury]. Everything about being in the hospital was fine up until they started preparing to roll me to the x-ray room on the hospital bed I'd been sitting on. The nurse said, "Keep your hands in," and memories came crashing in of being wheeled down the hall to deliver Jacob... I had to work on breathing, trying not to think about the memories and the déjà vu experience of [my husband] walking beside the bed as I was wheeled through door after door... (Myrna, April 2001)*

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If a parent has formed strong feelings of attachment for their unborn or newborn child, the likelihood of experiencing a perinatal death as traumatic is increased. As Speckhard (1997) put it, "of the many meanings that may be assigned to a pregnancy, parental attachment is the strongest, in terms of creating a context for its loss, or interruption, to be experienced as the traumatic death of one's unborn child" (p. 74). Thus, whether a perinatal loss is experienced as traumatic or not is dependent on the meanings that each parent attributes to the event. What is labelled as being a traumatic event is really "an indifferent phenomenon" if separated from the meanings assigned to it by an individual (Speckhard, 1997, p. 75). The possibility of pregnancy loss being traumatic has been largely ignored, despite the obvious physical trauma associated with it. This is primarily because miscarriage and perinatal loss have not been defined as events that defy normal expectations, such as war time experiences, natural disasters, and so forth.

Parents may attach many symbolic meanings to their loss, some of which can be viewed as predictors of increased risk that the parents will experience the loss as traumatic (Speckhard, 1997). As already noted, the potential for psychological trauma is increased if there is an assignment of meanings such as those that promote attachment to the foetus. The multiplicity of losses that can go along with a perinatal loss can add to this feeling of trauma – for example: the potential for loss of/threat to the couple's relationship; loss of parental or spousal role assignments; loss of control and/or belief in an orderly world; loss/threat of loss to subsequent fertility; loss of social status as a parental member of society; loss of a family member; loss of a positive self-concept based on one's fertility or one's nurturing and protective capacities; and loss of a sense of one's personal invulnerability (Speckhard, 1997). Each parent ascribes meaning to their experience in their own way, based on their personal history of losses, their life views, the response of others to their loss, and any number of other social, intrapsychic, and biological influences. It is these meanings that determine the traumatic potential of their loss. If a

parent does experience a perinatal loss as traumatic, the grief process is clearly made more complicated.

### 2.2.5 Disenfranchised Grief

*I sit in a support group meeting for bereaved parents, and I listen and wait as the other parents introduce themselves. Concentrating on breathing, trying not to cry, it is difficult to hear all that is being said. But the relentless pain of these other parents beats into my brain nonetheless. A daughter, dead now for 25 years...a son who died slowly and painfully of cancer at the age of 15...a 2-year-old granddaughter murdered one week before her grandfather was to meet her for the first time...a 4-year-old girl, perfectly healthy one day and dead two days later from a lethal virus...so much pain, so many senseless deaths. The introductions are making their way around the circle, and I begin to panic...I don't belong here, there are no others who've had a stillborn baby...wait, here's one...a young couple, looking like they've just emerged from a train wreck...a stillborn baby 2 weeks ago...the sympathy and support around the room is audible. Still, I'm worried about how to introduce my husband and myself...how does our loss compare to the rest of these parents? I know I have grieved profoundly, but maybe someone, even one other person in this room, will feel that my loss is not as bad as theirs...hell, I even wonder that myself after hearing their stories. It's my turn to introduce myself and my husband (who is too pale to say anything). "We lost our son, Jacob, a year ago on Thursday." Oh God, why couldn't I say he was stillborn? Am I ashamed because I dared to presume that my loss is as profound as is theirs? Do I really think these people won't accept my pain as legitimate?*

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- The mother of a dying baby, less than a week old, is advised by the paediatric cardiologist not to come to the hospital to be with her dying son..."There's really no point. There's nothing you can do." (Fumia, 2000, p. 32)
- "...[a friend] reminded me that [her doctor] recently lost a ten-year-old son...I felt embarrassed...To lose a ten-year-old, compared to an infant that you barely know..." (Fumia, 2000, p. 34)
- "A nurse speaks to us at the desk as we're going out. She is cold, impatient. She tells us we have to fill out a stillbirth form before we can be discharged. We put down our things. She pushes a pen and paper across the desk, which is so high I have to stand on tiptoe to see it. I feel the nurse's hostility. We are like blemishes on perfect fruit, and might infect the others...The form asks for the baby's name...Peter writes down a name...I'm not sure, but we are being rushed and there is no one to advise us." (Powning, 1999, p. 95-96)
- "No one counsels us. Someone tells us, in the hospital, not to have a funeral." (Powning, 1999, p. 98)

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These anecdotes from the lives of individual women, including mine, illustrate the concept of disenfranchised grief. Doka (1989) defined disenfranchised grief as "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (p. 4). Disenfranchised grief reflects a paradox, in that the very nature of the grief (being unsanctioned by society) creates additional hurdles for the



grief process because of limited or non-existent sources of support (Doka, 1989, 2002). This concept pertains to a variety of bereavements that are not recognised or sanctioned by society: *relationships that are not kin-based*, such as homosexual lovers, friends, neighbours, colleagues, stepparents; *relationships that are not defined as significant*, such as miscarriage, perinatal death, loss of a pet, abortions, children given up for adoption; and *individuals who are not perceived to be capable of grief* – young children, the very elderly, and intellectually disabled adults (Doka, 1989). The net result of an individual's grief being disenfranchised is the possibility of complicated bereavement. The usual emotions of grief (anger, guilt, depression, loneliness, hopelessness, numbness) can be intensified. Guilt over ambivalence in the relationship, which is common in many forms of bereavement, can be even more unbearable and difficult to resolve. And factors that would usually aid in the grieving process are absent (e.g., participation in funeral rituals, receiving sympathy from others).

The concept of disenfranchised grief includes both intersocial and intrapsychic components (Doka, 1989). The intersocial dimension occurs when society deems a person to have had an insignificant or minor loss, thereby denying them the mourning outlets and social supports typically available to bereaved persons. This disenfranchisement can influence an individual to intrapsychically disenfranchise themselves – that is, they may experience shame about the relationship or their grief response to it, or other emotions that inhibit their grieving process. This intrapsychic dimension, or self-disenfranchisement (Kauffman, 1989), does not necessarily involve the actual views of others, but the imagined views of society and/or the individual's own intrapsychic dynamics. Thus, the source of the disenfranchisement can arise from society or from bereaved individuals' own assumptions, which might be based on previous experience with societal views. The two dimensions are not neatly differentiated in reality, tending to blur together and mutually influence each other (Kauffman, 1989).

With respect to perinatal loss, Nichols (1989) provided a list of clichés and insensitive comments that parents often hear which are reflective of the disenfranchised nature of this form of bereavement: “You’re lucky you never took him home”; “You’re young, you can have another”; “You have your other children”; “Well, it happens in life” (p. 117). While insensitive comments are sometimes heard with other forms of loss as a result of western society's difficulty with death in general, the flavour of these comments suggests something beyond discomfort. Instead, they suggest that society has assumptions about perinatal loss that place it within the realm of disenfranchised grief.

The authors of many studies, case reports, and self-help literatures have discussed the disenfranchised nature of miscarriage and perinatal loss. Leon (1990) spoke of the “deafening

silence” that parents face after such losses (p. 57); others have called it the “conspiracy of silence” (DeFrain, Martens, Stork & Stork, 1990-1991; Lewis & Page, 1978), which I alluded to in previous sections. Rando (1986) noted that while the age of the child does define some specific problems and issues that parents face in their grief, the issue of age is essentially meaningless to bereaved parents. Despite this, there exists the “curious social phenomenon” of disregarding the significance of a parent’s loss if the child died at either end of the “child” continuum – that is, pre- or perinatally or in adulthood (Rando, 1986, p. 6). Medical practitioners and others in the helping professions have traditionally been both overly protective of parents and insensitive to parents’ grief because of ignorance about the significance of these losses. Kirkley-Best and van Dervere (1986) described a scenario, a composite of clinical experience with perinatal loss, in which a young family member dies:

The death is handled quickly and abruptly, and the child is never mentioned again. The children in the family are given a cursory explanation, and no further communication that the child ever existed. Furthermore, the grief of family members is not acknowledged either by others in the family or by friends and relatives. The death is considered a minor and insignificant event. Children born subsequent to the child are never told that the child existed, and may only find out years later. (p. 419)

These authors pointed out that if this scenario was about an older child or any other loved one who died, a clinician would consider it a dysfunctional family. With a perinatal death, this scenario was common and encouraged by medical professionals up until a short time ago. In many cases of miscarriage, medical professionals continue to neglect the emotional needs of their patients (Lee & Slade, 1996). And, as my own story above suggests, parents can be influenced by our society’s continued comparison of different forms of bereavement, a rationale that goes something like this: a miscarriage is not as bad as a stillbirth, which is not as bad as if you had a chance to get to know the infant, which is not as bad as the death of an older child. This hierarchical ranking of degrees of pain and grief undoubtedly continues to influence the grief of parents bereaved of a stillborn or newborn child, even with the advent of improved acute care.

The hierarchical comparison of the grief of different forms of bereavement speaks to Corr’s (1998-1999) suggestion that disenfranchisement extends not only to types of relationships that are unsanctioned, but also to the various aspects of grief itself. For example, our western society has a tendency to approach grieving individuals with a variety of assumptions about the “proper” way to grieve. Bereaved individuals, particularly those falling into a disenfranchised grief category, often receive messages such as: “Your grief is not acceptable to us in some ways,” or “Your mourning has lasted too long,” or “Your grief is in itself a



symptom of psychic disorder or lack of mental health’,” or “Your mourning should be finished and over with by now” (Corr, 1998-1999, p. 17).

Malacrida (1999) discussed how societal assumptions about the insignificance of perinatal loss extend to gaps within the major societal institutions that should be serving and helping bereaved parents through their grief. Every potentially important source of support, including the family, clergy, the funeral industry, workplaces, the medical profession, and religious communities have yet to whole-heartedly demonstrate their acceptance of perinatal loss as a significant death. For example, families and friends that would have showered the new parents with money and gifts instead avoid the parents, not knowing how to respond to the loss or believing it was only a minor loss. The medical community in some locales continues to withdraw resources following a perinatal death (e.g., mothers may not be given the same level of postnatal home care as other postpartum women; parents are not given answers about cause of death because of limited resources for things such as autopsies). Malacrida suggested that these various factions of society need to adjust their views of perinatal loss in order to prevent further costs to society in terms of secondary mental and physical health problems experienced by parents whose grief has been disenfranchised and neglected.

### 2.3 A Parent's Grief: An Exception to the "Grief Rules"

In this section, I will discuss a few selected theories of bereavement that have particular relevance to the unique problems of grief faced by bereaved parents, including those losing a baby in the perinatal period. I start with a glance at the benchmark stages and phases that professionals use to judge a bereaved individual's grief progress. Included in this discussion is a brief consideration of the limits of applicability of these models to parental bereavement. I then look at some examples of alternative theories that address the issue of long-term grief and grief resolution, and whether parents ever “let go” or “get over” their grief in the sense proposed by many grief theories.

#### *2.3.1 Stage and Phase Models*

Since early theorists began studying grief<sup>8</sup>, normal grief has generally been conceptualised as a series of stages or phases which include a description of symptoms as well as the tasks of grief required for healthy resolution (Shuchter & Zisook, 1993). A variety of stage models have been proposed, with perhaps the most popular being Elizabeth Kubler-Ross's five-

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<sup>8</sup>The following definitions will be used here: Grief refers to “the emotional response to a loss”; Bereavement is “the objective situation of having lost someone significant”; and Mourning refers to “the actions and manner of expressing grief, which often reflect the mourning practices of one's culture” (Stroebe, Stroebe, & Hansson, 1993, p. 5).

stage model (Kubler-Ross, 1969): denial and isolation, anger, bargaining, depression, and acceptance. Stage and phase models are cited widely in lay literature as well as treatment literature for professionals working with the bereaved. These models often come with the warning not to take such stages or phases too literally, since in reality grief is not a linear process with clearly delineated start and endpoints for the various symptoms and emotional phenomena experienced. Rather, these models are intended to provide general guidelines to assist the clinician, but not to rigidly determine where an individual “should” be in the grieving process (Sanders, 1999; Shuchter & Zisook, 1993). A number of researchers have offered a variety of stage and phase formulations, with the general progression of: a period of shock, disbelief, yearning and searching; followed by disorganisation, emotional extremes, social withdrawal, and cognitive dissonance; and ending with some form of grief resolution (Gilbert & Smart, 1992; Shuchter & Zisook, 1993).

While these models of grief have a useful purpose as general guides to the grief process, many researchers in the area of parental grief have expressed concerns that these models do not adequately reflect a parent’s experience of losing a child. In particular, the existence of an “endpoint” of recovery has been questioned in parental bereavement, with most parents experiencing an ever-changing grief process indefinitely, long beyond the usual prescription of 2 to 4 years (at the very most) for “recovery” from grief (e.g., Braun & Berg, 1994; Farnsworth & Allen, 1996; Klass, 1988). If anything, parental grief appears to intensify over time (De Vries, Davis, Wortman, & Lehman, 1997; Rando, 1986), something that is not accounted for by most stage and phase models and would be labelled *pathological grief*, *complicated bereavement*, or *unresolved grief*. Rando (1986) suggested that the characteristics of relationships and other factors that lead to unresolved grief are necessarily found in the parent-child relationship, and as such, parents are likely, by definition, to experience the various types of unresolved grief. For example, the death of a child is viewed as an unspeakable, horrifying loss in our society, leading parents to have a particularly difficult time accepting the reality of the death. This is made more likely if they do not receive adequate social supports, which is often the case. As well, the parent-child relationship, with the responsibilities intrinsic in being a parent, sets parents up to have difficulty resolving their anger and extraordinary guilt, which is a feature of *distorted/conflicted grief*. The parent-child relationship is also characterised by dependency and investment in the relationship, and the death of a child is most often unexpected; these are all risk factors for *chronic grief*. Thus, a parent’s normal grief response, by virtue of the intrinsic characteristics of the parent-child relationship, automatically fits into what has traditionally been labelled complicated bereavement. Further, besides the negative aspects of continuing grief, it

has also been noted that many parents experience positive changes over time following a child's death – the loss, in a sense, becomes the major organising event in a parent's life (Rubin, 1993). This, too, is not accounted for in traditional grief models.

A parent's grief, then, does not fit the “healthy grief” mould as prescribed by traditional grief theories. Given the unique grief patterns of parental bereavement, patterns that differ even within the realm of parental bereavement as a whole (e.g., differences based on the age of the child at death), De Vries and colleagues (1997) encouraged researchers to “move beyond the conventional temporal markers and indicators of adjustment in their assessment of bereavement trajectories” (p. 114). Neimeyer and Keesee (1998) pointed out that a “new wave” of grief theory has emerged in response to the growing dissatisfaction with traditional theories. These newer models have the following elements: (1) scepticism about the universality of a predictable grief trajectory leading to adaptation; (2) a shift away from the assumption that “letting go” is a requirement of healthy grief resolution; (3) more emphasis on the cognitive processes of grief in addition to the emotional responses; (4) increased understanding that loss can profoundly impact a person's identity and lead to changes in his/her self-definition; (5) awareness of the personal growth-producing nature of bereavement; and (6) consideration of the broader impact of loss on families and cultural groups (Neimeyer & Keesee, 1998). In the next section I provide a glimpse of some grief models that have shifted their focus in these ways.

### *2.3.2 Examples of Alternative Grief Models*

#### *2.3.2.1 A Multidimensional Approach*

Shuchter and Zisook (1993) proposed a multidimensional approach to the assessment of normal grief, which, although directed toward spousal bereavement, is a good example of an alternative to the more linear or phasic grief models. Their model consists of six comprehensive dimensions: (1) emotional and cognitive response to the death of the spouse, including shock, the pain of grief, anger, guilt, intrusive images, etc.; (2) coping with emotional pain – in terms of numbness and disbelief, emotional control, altered perspectives, faith, activity, and so forth; (3) the continuing relationship with the dead spouse – by maintaining ties through location of the spouse (spiritually and burial site), continuing contact (e.g., “talking” to their spouse), rituals, living legacies, memories, dreams; (4) changes in functioning – in terms of health, work, social life; (5) changes in relationships – with family and friends; and (6) changes in identity – such as growth in emotional strength and modified belief systems and assumptions. Shuchter and Zisook presented their model as an alternative way of understanding the diversity of grief experiences across types of losses, cultures, and over time. In particular, this model allows for the possibility that many individuals never completely resolve their grief, but have significant aspects of the

grief process continue indefinitely despite being able to function in daily life. The multidimensional nature of this model also speaks to the complexity of the grief process.

#### *2.3.2.2 Grief as a Process*

Other grief theories have shifted from describing grief symptoms and the temporal trajectory of grief to explaining the phenomenon of grief as a process. Parkes (1993) suggested that the various theories of grief do not necessarily conflict with one another, but each has its place in explaining or describing particular aspects of grief. Parkes approached the human reaction to a major loss by viewing it as a psychological trauma that invalidates one's basic assumptions about life. These assumptions and expectations are part of a cognitive schema that Parkes called the *assumptive world*, and at a basic cognitive level they are assumed to be true based on past experience. With the death of a loved one these assumptions are called into question and must be revised in order for the person to accept what he or she now knows about the world, and to learn to live without the loved one. Grief, then, is the process of adapting, revising, and reorganising these assumptions, and coming to a new theory of the world that helps to explain their loss. Conceptualising grief in this way helps to account for the complexity, diversity, and ongoing nature of the grief of some individuals.

#### *2.3.2.3 A Parent's Grief: Broken Bonds or Continuing Bonds?*

Prompted by the observation that a parent's grief does not have a final resolution as described by many grief theories, some researchers have suggested that parents never completely "let go" of their child. Klass, Silverman, and Nickman (1996) proposed the idea of "continuing bonds" to explain this aspect of grief, not only for parental bereavement, but for other major losses as well – the death of a spouse, a parent, and the experience of adoptees who have "lost" their birth parents. The suggestion is that the relationship with the lost loved one does not completely end, although the intensity may diminish with time. Some bereaved individuals appear to actively memorialise, remember, and allow the person who has died to influence the present indefinitely. This is proposed to be a normative and healthy response, an ongoing and ever-changing attempt to stay connected with the deceased throughout the survivor's lifetime. Grieving for the deceased is viewed as a cognitive as well as an emotional process that does not end but affects the bereaved for the rest of his/her life, changing and transforming them and their continuing connection to the deceased along the way. It is further suggested that the concepts of grief resolution, recovery, or closure should be replaced with the term *accommodation*. This implies a dynamic, ongoing process in which the bereaved make sense of the death and their history with the deceased, and how the deceased continues to fit into their lives.

The idea of continuing bonds with the deceased was proposed largely in response to traditional theories that emphasised the importance of breaking bonds with the deceased as a key task of grief, and that maintaining attachments was symptomatic of pathology (Klass, Silverman, & Nickman, 1996). Freud was the first to suggest that mourning (in the sense of breaking child-parent Oedipal attachments) involved a process of “decathecting” in which attachment ties to a loved one are severed in order to release libidinal energy (Klass et al., 1996). Klass and colleagues pointed out that this concept of severing attachments was taken up by other theorists (e.g., Bowlby’s attachment theory) and applied to the grief of losing a loved one. They contended that the resulting breaking bonds hypothesis, which proposes that bonds with the deceased need to be broken for the bereaved to adjust and recover, has led to inappropriate expectations on the part of helping professionals about what is “normal” and “healthy” grief. They suggested that counselling and therapy principles have whole-heartedly adopted the view that bereaved persons must let go of their attachments to the deceased for true recovery to take place, and this can be more damaging than helpful.

Fraley and Shaver (1999) commented on the continuing bonds model, indicating that it should not have to be defined in contrast or in opposition to Bowlby’s attachment theory, because of clear consistencies between the two. They suggested that Klass and colleagues uncritically accepted some “continuing bonds” that are potentially psychologically unhealthy for bereaved individuals. For example, the continuing bonds position does not distinguish between secure and anxious dependence in relationships, and the greater vulnerability faced by people who were anxiously or ambivalently attached to the deceased person. That is, Fraley and Shaver suggested that not all forms of dependence are adaptive, and not all signs of prolonged grief and psychological pain years after a loss should be considered healthy continuing bonds (e.g., intrusive thoughts over several years, feeling the deceased person’s presence in a way that is not comforting). While continuing bonds in the form of positive memories, recurring pangs of grief, and ongoing rituals may be healthy, other signs of long-term grief may be a source of serious psychological difficulty rather than a healthy and natural part of the grief process.

Other researchers have taken a similar position regarding a parent’s continuing bonds to their deceased child. Bernstein (1998) spoke of the need for parents to undo the emotional bonds to their child while at the same time finding some way to maintain healthy connections. She indicated that some bonds need to be released in order for healthy adaptation to take place, but that maintaining some attachment, through altruistic acts, establishing memorials, and devising other ways of maintaining bonds is also necessary for healthy renewal and adaptation following a child’s death. “The darkness of grief is a connection to the deceased

that is hard to relinquish” (p. 21), but allowing oneself to let go of the bitter sorrow is one step toward adaptation. Bernstein pointed to the importance of a parent recognising that allowing him/herself to enjoy life again is not a betrayal to the deceased child. At the same time, letting go of the darkness of grief does not mean that other healthy bonds cannot be kept and nurtured. Maintaining some connections to the deceased child can help parents in the struggle to find new meaning in their lives.

## 2.4 Making Sense of Death

The loss of a child is a particularly difficult (or impossible) loss to “let go” of, as seen in the previous section. Some have suggested that this occurs not only because of the intensity of the parent-child relationship, but also because the loss does not make sense within the framework of what most people believe about how the world works (Weiss, 1993). The death of a child is a crisis event in which the “social stock of knowledge” does not contain a satisfactory explanation, making it almost impossible for some parents to cognitively and emotionally accept the loss, and to find a new way of making sense of the world (Braun & Berg, 1994, p. 108). For these parents, the search for meaning, or meaning-making process, is a particularly difficult part of the grief.

Neimeyer and Keesee (1998) suggested that the key deficiency of traditional grief models is their assumption of universality in grief, with similar responses across individuals at the emotional level. They proposed “meaning reconstruction” as an alternative model of grief, with the assumption that meaning reconstruction or meaning-making in response to a loss is central to the grieving process. In contrast to traditional models of grief, a meaning reconstruction view emphasises “the subtle nuances of difference in each griever’s reaction, so that no two people...can be presumed to experience the same grief in response to the same loss” (Neimeyer & Keesee, 1998, p. 228). With this view, the themes and meanings that individuals ascribe to their experiences are varied and complex, rather than being readily predictable and universal. As well, loss is considered an event that can traumatically challenge one’s basic assumptions about the world. Further, grief is seen as an active process, in which the bereaved have choices about how they will proceed in their grief. And finally, a meaning-reconstruction model accounts for the larger social and cultural context within which an individual grieves.

In this section I describe the meaning-making process. I first explain how an adverse or traumatic event results in a sense of meaninglessness, and then outline the process of finding and creating meaning. This is followed by a consideration of obstacles to finding meaning, with special consideration of how this applies to the loss of a child or baby. I then discuss how some



people are able to find or create positive meaning out of a loss or trauma, and the changes and transformations that take place along the path of meaning-making. Finally, I present a way of conceptualising the meaning-making process in terms of narratives.

#### *2.4.1 The Trauma of Meaninglessness: The Purpose of Meaning-Making*

People search for meaning in order to explain many types of severely adverse or traumatic experiences – such as someone else’s behaviour (e.g., child abuse), random events (e.g., natural disasters, accidents), and significant losses (Lempert, 1994). It is universal for people to adopt and attempt to maintain the belief that what happens in the world makes sense on the basis of a logical relationship between events and people’s actions or inactions (Janoff-Bulman & Frantz, 1997). This belief or set of assumptions has variously been referred to as the “assumptive world” (Parkes, 1993; Janoff-Bulman, 1992; Janoff-Bulman & Franz, 1997; Matthews & Marwit, 2003-2004), “life scheme” (Nadeau, 1998), or “meaning structures” (Braun & Berg, 1994). The assumptive world consists of a number of fundamental assumptions which are tacitly accepted as true – such as the view that people are not harmed arbitrarily, that bad events are not random, that a person brings on his/her own problems, and that malevolence is not haphazard (Janoff-Bulman & Franz, 1997). These assumptions are generally very stable, but can be upset by a significant trauma (Nadeau, 1998). The shattering of the assumptive world leaves a person with a sense of meaninglessness and an acute awareness of one’s terrifying vulnerability (Janoff-Bulman & Frantz, 1997). The result is a triggering of the search for meaning, a sense of urgency to find answers to an infinite number of concrete and existential questions. This attempt to find a way to accommodate traumatic experiences into a new understanding of reality appears to be a basic part of human nature (Braun & Berg, 1994).

The purpose, then, of searching for meaning following an adverse experience is to recreate one’s basic understanding of the world such that life again becomes imbued with meaning (Janoff-Bulman, 1992; Nadeau, 1998). In terms of the death of a child, Bernstein (1998) suggested that because such an event does not fit with a parent’s previous understanding of life, the task of grief is not to “get over” the loss, but to adapt their view of the world to accommodate their experience. Bernstein’s study of 50 bereaved parents suggests that parents who are able to find new and positive meaning in life manage to adapt more readily, and in a healthier manner, to their new reality without their children. This struggle to find answers is said by some to be central to the grieving process, and the ability to find meaning greatly affects how well people come to terms with a loss (Matthews & Marwit, 2003-2004; Miles & Crandall, 1983; Nadeau, 1998). Speckhard (1997) pointed out that not only does a traumatic experience like the death of a child lead to a sense of meaninglessness, but that the meaninglessness itself

is traumatic and can lead to a pathological response over time if meaning cannot be found. People are generally quite willing, or at least able, to endure pain and deprivation if there is some clear meaning, purpose, or hope for the future (Baumeister, 1991). However, if these meanings do not exist or cannot be found, the pain of meaninglessness can be unbearable. In an extreme example, Viktor Frankl, a concentration camp survivor, showed that if a person is unable to find meaning after experiencing severe trauma, there is no reason to go on living (Frankl, 1992).

#### *2.4.2 Re-establishing Meaning: The Process of Meaning-Making*

In order to find new meaning once the assumptive world is called into question, a person must find some way to re-order his or her reality to accommodate the new information (i.e., the child's death and all the meanings that are shattered with it) (Braun & Berg, 1994). Parents must reorganize their assumptive world to incorporate the new reality that the child is dead and life must continue without him/her, despite the belief it should not be that way. In studying the meaning-making process of bereaved mothers, Braun and Berg (1994) found that if mothers' original assumptive world accounted for the death of a child (e.g., framing it in terms of God's plan, recognizing and accepting that bad things can happen to anyone), they did not experience as much discontinuity or threat to their sense of meaning as did mothers whose assumptive world had no explanation for a child's death. Although their intensity of grief was no less, the terror of meaninglessness did not occur for them. For those who did not have a readily available and meaningful explanation, disorientation resulted: feeling disconnected from the world, intolerant of others' complaints, viewing life as fragile and vulnerable, loss of hope for the future, feeling a lack of personal control over events, and a loss of purpose in living. For these parents, reorientation could only occur by adjusting their assumptions to account for the child's death, thereby restoring a sense of meaning and purpose in life. How, then, do these adjustments occur?

Janoff-Bulman and Frantz (1997) suggested that the initial response of a person to a shattering of their assumptive world is to try to validate the original assumptions and minimize the sense of randomness of the world. Thus, the person re-evaluates his or her own role in the event by searching for meaning: laying blame for the event on themselves, someone else, attributing it to God's plan, or looking for ways it could have been prevented. A large part of minimizing the crisis of meaninglessness over time is dependent on the person's ability to shift the search for meaning from basic questions like these to questions of significance and value in one's life. A person must attempt to move past the "terror of a meaninglessness universe" to believing that he or she has a life of value and worth.



In considering parents' narratives of losing a child, Rosenblatt (2000) suggested that the starting point of finding new meaning and purpose is recognizing the reality of the death. The unnaturalness of a child's death shakes up the parent's sense of the orderliness of life, faith in nature, meaningfulness of life, the expected sequence of life, and of all that is natural. The meaning-making process must take into account this unnaturalness and the unreality of the death. As well, the parent comes to identify what has been lost, recognizing their many losses – loss of future, lost opportunity, and so on. Rosenblatt stated that until a person can name what is lost, he/she cannot make meaning or give meaning to the death. Another part of the meaning-making process is the search for positive meanings, and coming to recognise that not all that came out of the death is negative. The ability to find positive meanings appears to help parents emerge from the most despairing episodes of grief. Finding positive meaning is not automatic, but is essentially a conscious choice.

Rosenblatt's study also showed that parents accomplished some of their meaning-making via material objects that linked them with meanings about the past and meanings about life since the death. They also found meaning through places that held meaning during the child's life, or were linked to the death, or had significance since or because of the death. These material and contextual meanings, like the positive meanings, did not come automatically, but were actively searched for and created by parents.

Nadeau (1998) provided further insights into how meaning-making is carried out. In studying the meaning-making process of families in response to the death of a loved one, Nadeau found that a family's telling of the events surrounding the death was like a litany, a meaning-laden story. These meanings were of two types – existential meanings addressing the meaning and purpose of life; and meanings related specifically to the death and what it meant to the individual/family. The latter meanings had a bearing on how well families managed, and how difficult it was to go on living without the loved one. Speckhard's (1997) theory of the trauma of perinatal loss is consistent with this finding of Nadeau's, in terms of the suggestion that positive resolution after perinatal loss can only be achieved if parents come to terms with what the meaning of the pregnancy and its loss was for them. Speckhard proposed that some of these meanings can be found through mourning and death rituals, naming the baby, and not denying one's grief. Yet, many parents need to specifically discuss any remaining negative meanings surrounding the event if it was perceived as a traumatic event.

#### *2.4.3 Blinded by the Meaninglessness: Obstacles to Meaning-Making*

In previous sections I alluded to the many obstacles to meaning-making that can occur with a perinatal loss. Speckhard (1997) summarized these obstacles in terms of four factors that

can be a part of a perinatal loss experience: attachment in pregnancy is often not socially recognized; the presence of survivor guilt with respect to how the death occurred, or otherwise experiencing the loss as traumatic (e.g., actual or fantasized images of the death event); the death can symbolically signify more than just the loss at hand, including a multitude of other losses such as the loss of dreams for and fantasies about the child; and finally, the loss of a pregnancy and all its associated symbolic losses is often socially disenfranchised, with few rituals available to aid parents in the meaning-making process. Of these factors, Leon (1990) emphasised the need to consider social forces in bereaved parents' lives – including medical personnel, family, and friends – in order to fully understand a woman's experience of pregnancy loss, and her psychological outcome. This unique constellation of issues can result in a difficult meaning-making journey in which parents must work to affirm for themselves and others that they went through a pregnancy, labour, and delivery, that a baby did exist, and that their loss was a significant one.

Social influences on a person's meaning-making can often serve as obstacles to this process. Nadeau (1998) pointed out that individuals' definitions and meanings attributed to a death are highly influenced by others, rather than being generated in a vacuum. Braun and Berg (1994) highlighted some social factors that make it impossible to account for a child's death within parents' existing world views. In general, shared meanings of society do not acknowledge the possibility of death of a child, and as such, there are no explanations to account for such an event. The following societal views are likely to negate the possibility of a child's death, making it more difficult to make sense of: (1) parenthood is often a planned for, personal, emotional investment, making children in Western culture central to a parent's life meaning and identities; (2) beliefs and assumptions about basic nature of life – e.g., the American dream, fairness and justice; (3) the perception that all of life's real meaning is to be realized in the course of one's life span (therefore the old should die, not the young); (4) the belief that people are the sole determiners of their own success or failure in life; and (5) the general denial of death in Western culture – death is denied or removed from everyday routines of the living; therefore death of a child is viewed as an obscenity.

Another important influence on the meaning-making process following bereavement is a person's spiritual beliefs. Braun and Berg (1994) found that parents who held the belief that there is no existence beyond the realm of the life span could not find meaning that accounted for the death of a child. The logical extension of this belief is that a person must achieve all of life's meaning within their life span, and so a premature death snuffs out life's meaning. In contrast, Braun and Berg spoke of one mother whose belief system led her to differ from the rest of the

mothers in terms of having sorrow and pain but no crisis of meaninglessness. This mother expressed early and complete acceptance of the loss of her son, based on the following spiritual beliefs which she held prior to her son's death: she had a strong belief in an afterlife, and so believed her child is with God; she viewed herself as powerless under an all-powerful God who only makes the best decisions for us; and she believed that order is maintained by God ("He has His reasons").

#### *2.4.4 Seeing Past the Meaninglessness: Positive Transformations and Identity Changes*

*I would never wish this tragedy on my worst enemy, however, I would never trade the experience for anything in the world. We are better people and better parents because of what [our son] continues to teach us. (Steele, 1999, p. 2)*

Parr (1998, p. 96) quoted a woman, who was sexually abused as a child, as she explained her eventual decision to return to higher education as a mature student:

I sort of came to a point where I thought "I can either carry on the way that I am going and make a total mess of my life or try and get something positive from the negative" - try to get to a position where I can actually carry on with my life...

The fact that this woman experienced abuse rather than bereavement speaks to the striking similarity in the psychological response of people to adverse events in general. Bereavement researchers have discussed a similar "turning point" that occurs in grief in which the bereaved either move forward, continue without making changes, or choose the extreme option of giving up and dying (not necessarily a conscious choice) (Sanders, 1999). When individuals who have experienced traumatic events are able to resolve issues of meaning, they are more likely to choose to "move on" in the sense described by the woman above (Baumeister, 1991). Moving on does not mean resuming a previous level of functioning, as discussed above in terms of a parent's enduring grief. It does, however, mean that the person has been able to make sense of the experience to some degree, and is able to function in daily life (Weiss, 1993). And some individuals undergo positive changes in their life and transformations to their identity that derived from their experiences of great pain and meaninglessness (e.g., Farnsworth & Allen, 1996).

De Vries and colleagues (1997) suggested that too much attention has been focused on the negative outcomes of parental bereavement, such as depression, to the exclusion of these more positive outcomes. As such, the evolution of these positive aspects and outcomes of the meaning-making process are not well understood. This is an unfortunate gap in understanding, given the common reports that bereaved parents often develop altered perspectives on life (in a positive sense), become more compassionate, and become more assertive and courageous – despite the ongoing struggle with grief (e.g., Bernstein, 1998; Boyle, 1997; Braun & Berg, 1994; Talbot, 2002; Tedeschi & Calhoun, 2004). Even parents who continue to struggle with issues of

meaning will have moments of recognising what is really important in life, the importance of relationships, and their own value in life (Braun & Berg, 1994; Janoff-Bulman & Franz, 1997). As the meaning-making process evolves, many individuals choose to focus more on close relationships and/or altruistic social causes as a result of their newfound meaning, while others turn to spirituality (Braun & Berg, 1994; Leon, 1990). Janoff-Bulman and Franz pointed out that predictors of successful meaning-making are still elusive; while self-esteem and attachment issues are likely involved, they are not particularly helpful in understanding the adjustment process following trauma. This is especially the case when one considers that traumatic experiences can have both a positive and negative impact on the same survivor – they can experience both shattered assumptions/awareness of their own vulnerability, as well as the pleasure of a “new-found appreciation of life and sense of value and meaning in their daily existence” (Janoff-Bulman & Franz, 1997, p. 103).

#### *2.4.5 Meaning-Making Through Narratives*

Bruner (1990) suggested that it is time for psychology and other social sciences to take seriously what he calls “folk psychology” in the pursuit of understanding human beings and their experiences. He proposed that all cultures have a folk psychology, which is a system of beliefs and desires which organises their knowledge, experiences, and transactions with the social world. Folk psychology takes on a canonical status in a given culture, by summarising not only how things are, but how things should be as well. Bruner suggested further that the organising principle of folk psychology is narrative rather than conceptual. That is, people use narratives, or stories that they tell to themselves and others, as a way of organising their experiences within a folk psychology system of understanding the world. However, it is only necessary for a person to construct such narratives when their constituent beliefs in a folk psychology are violated. When a person’s experience does not fit the folk psychology model of “how things should be,” narrative understanding is then needed to make sense of their experience.

In the realm of grief theory and research, the suggestion has been made that creating narratives about a deceased loved one’s life is a key process in the reconstruction of one’s identity during grieving (Riches & Dawson, 1996). Bereaved persons have reported being aware of the need for re-storying because of a sense of having no meaning and no self without the ongoing narrative that existed before the loved one’s death (Steeves, Kahn, Wise, Baldwin, & Edlich, 1993). Consistent with the previous discussion of meaning-making, grief can therefore be seen as the painful search for a new narrative (containing new meanings) that fits the new reality. The meaninglessness of a death shatters the value of the old narrative, so that some of the pain of grief is the pain of not having a coherent story to make sense of or understand one’s

experience. In other words, the meaning-making process or search for meaning can be conceptualised in terms of narrative – a bereaved person’s need to adapt their personal narratives to the new reality without the deceased person (Steeves et al., 1993).

In essence, then, the ongoing “storytelling” that an individual engages in following a significant loss serves as the vehicle for his or her meaning-making journey, with the ultimate destination being a coherent story that accommodates the new reality and eliminates the sense of meaninglessness. The purposeful act of storytelling can lead to irrevocable changes and transformations in the person’s identity, despite ongoing questions of meaning and the various obstacles to meaning-making encountered along the way (Riches & Dawson, 1996; Neimeyer, 2001). With this connection between meaning-making and narrative in mind, I now turn to a description of the design and methodology of this study.

### 3. RESEARCH DESIGN AND METHODOLOGY

#### 3.1 This Study

The central aims of this study were twofold: first, to explore parents' narratives of perinatal loss to arrive at a better understanding of long-term grief and the meaning-making process with this form of bereavement. How do parents re-story their lives to make sense of their experience? Are they able to? How do they make sense of the loss in a positive or negative way, and what hurdles or supports help or hinder this process? What are the world view changes and transformations of self that take place as parents travel along their meaning-making journey? By adopting a narrative approach, this study sought to answer these questions in two ways: First, individuals tell stories to themselves and others in order to make sense of their experiences, and their stories are also central to the process of identity transformations and changes (Riches & Dawson, 1996). Exploring parents' narratives will therefore shed light on their meaning-making journey and transformation process. Second, after listening to parents' undirected storytelling in full, I asked them to specifically reflect on their search for meaning, providing an opportunity to view the process from their eyes.

These levels of understanding also worked toward fulfilling the second aim of this study: to move beyond an intellectual understanding of perinatal loss and enter into the experience (Ellis & Bochner, 1992) as it is understood by the parents themselves. Given the longstanding disenfranchised nature of this form of loss, and the characterization of the disenfranchisement of grief as being a form of empathic failure (Neimeyer & Jordan, 2002), eliciting an empathic understanding of the experience of perinatal loss seems particularly relevant.

This study is unique in a number of ways. First, the few studies that have identified the search for meaning in perinatal loss and the positive transformations that can take place have not explored these processes in depth, or in a way that preserved the individuality of participants (e.g., Boyle, 1997; Gilbert & Smart, 1992). The common anecdotal report of positive changes and transformations of self in the bereaved has not only been neglected in the perinatal loss research literature, but in bereavement studies as a whole. Instead, the focus of most bereavement research has been on pathology, negative emotions and outcomes, the grief trajectory, and so on (DeVries et al., 1997), with an awareness of personal growth and positive transformations just recently emerging (Calhoun & Tedeschi, 2001; Neimeyer & Keesee, 1998).

A better understanding is therefore needed of the transformative potential of grief and resiliency of the bereaved.

Further, other qualitative studies of perinatal loss have not approached the experience from a narrative perspective, which invites parents' words and "expert" insights more fully into the research. Unparalleled in any other research method, a narrative inquiry has the power to shape meaning and preserve the intensity of the lived experience (Ellis & Bochner, 1992; Emihovich, 1995; Kiesinger, 1995; Ellis, 2004). Narratives grant us access into people's innermost cognitive and emotional ways of understanding the world, and provide a window into their identity and personality (Lieblich, Tuval-Mashiach, & Zilber, 1998). Unlike qualitative methods that break participants' stories into themes and categories of meaning, narrative methodologies preserve the context of and manner in which participants tell their stories, thereby preserving more of the individual's identity (Rosenwald & Ochberg, 1992). Moreover, the taboo our society places on talking about death, particularly one that is not widely recognized as significant, deters perinatally bereaved parents from telling their stories. By adopting a narrative approach, parents were invited to share their stories in a way that would not have been possible with other qualitative research methods.

There have been a few parental grief studies that have considered the meaning-making process with qualitative methodology (e.g., Braun & Berg, 1994; Rosenblatt, 2000). Rosenblatt (2000) was the only researcher to take a narrative approach, studying narratives of 29 parents who had lost a living child (ranging in age from birth to 33 years, and one stillborn baby). Rosenblatt's analysis was essentially a thematic analysis carried out on narratives with the goal of identifying broad commonalities across stories, rather than being an analysis that preserved the diversity of experience and the individuality of each participant, as I did in this study. Further, the unique hurdles faced in perinatal loss (e.g., disenfranchised grief, nebulous relationship with the baby, etc.) make it important to explore the potentially different meaning-making processes of these parents. As some parental grief researchers have suggested, the age of a child at the time of death can lead to qualitatively different experiences of loss, depending on the unique age-related aspects of the loss and the meanings assigned to it (De Vries, Dalla Lana, & Falck, 1994; Rando, 1986)

Another unique aspect of this research has to do with the variety of individuals I invited to participate. Previous studies have focused primarily on mothers' grief response to perinatal loss, to the exclusion of fathers. Further, most studies have not considered long-term grief, or the diversity of experiences that could be expected amongst parents whose losses occurred in recent years in contrast to those whose losses occurred decades ago when the



disenfranchisement of this form of loss was more extreme. With the goal of exploring the full range and diversity of experiences of perinatal loss, I gathered stories from both men and women, as well as parents whose losses occurred recently or decades ago.

Finally, my personal experience of perinatal loss and my decision to incorporate my experience into this study via a semi-autobiographical, evocative narrative approach makes this study unique within the perinatal loss literature. In the following section I provide my rationale for this approach.

### 3.2 Revealing a Researcher's Personal Experience

*"...At times, I literally cringed while reading, thinking, 'Don't say that! There will be people who read this who will not respect you for it, and you've made yourself vulnerable to them.'" (Krieger, 1991, p. 148)*

To many social scientists who come from an experimental/quantitative tradition, the inclusion of my personal experience in this study may seem foreign, radical, and even unscientific. Even those who consider themselves qualitative researchers may find my approach overly personal and subjective. I was trained to do research within a positivist tradition. This tradition became an essentially unquestioned part of my assumptions about my topics of research very early on in my academic career. As a result, when I began exploring the world of qualitative methodology, I had a difficult time shifting my thinking to this "new" way of researching. On a personal level my instincts and emotions were telling me that the approach I have taken for this study is the "right" one. My "research self," on the other hand, had a much more difficult time coming to accept this post-modern, non-positivistic, non-quantitative, *subjective* approach to research.

*The people who object to the personal material are not especially articulate about their objections. They just don't like it. I think they are embarrassed by it. They think it is unseemly. They think it is inappropriate. It is not social science. It's not academic and authoritative. It's too confessional. It's self-indulgent, narcissistic, unnecessary, and superfluous. That is definitely what they convey. (Krieger, 1991, p. 194)*

*~ a sociologist interviewed by Krieger*

*In science, as I think we have all been trained, we bend over backward to pretend the researcher is not even in the room. You are writing down what people do, counting off how many times they look or smile. The unspoken oath is, we are all going to pretend that the researcher is invisible and objective, that the researcher is a machine... I feel passionately about what I study. Sometimes that embarrasses me, if I am giving a talk for instance. I guess I feel embarrassed because I feel people will think I would contaminate what I do, if it has anything to do with me. It should have nothing to do with anything... The training we get in science is to keep yourself out. I would like to think that I would not have totally bought the training, hook, line, and sinker. But I think I have, much more than I know. (Krieger, 1991, p. 240-242)*

*~ a psychologist interviewed by Krieger*



My own initial discomfort with including my personal experience in this work fits in with a larger debate that has been brewing for a number of years regarding the place of the researcher's self in social science research and scholarship. As the quotes above reflect, some social scientists have found themselves accepting, yet questioning, the traditional view that the researcher should be objective and invisible and should only report the facts, whether the data are quantitative or qualitative. This view prescribes that the research should be about those who are studied, not about the researcher. Increasingly over the past few decades, however, researchers across the disciplines have begun to recognise that it is the researcher's self that guides all research (e.g., Farnsworth, 1996; Gilbert, 2001; Parr, 1998). Some suggest that because of this inevitable influence of the researcher's motivations, views, values, and personality, the proper and valid thing for the researcher to do is to be as transparent as possible about his or her personal qualities and how they might influence one's research (e.g., Gilbert, 2001; Krieger, 1991; Parr, 1998; Peshkin, 1988).

Krieger (1991) argued that social scientists invariably and unavoidably are talking about themselves when they discuss others in their research. She suggested that the self-reflective nature of our statements is unavoidable; it is human nature to try to understand others by projecting ourselves onto them to some degree. She took the view that there is no correct balance between self and other in a study, but that there are simply different ways of expressing or using the self within social science research. When reading social science research, for Krieger what matters is not making judgements about whether the researcher talks too much or too little about self, but whether they talk about self, other, and the world in a way that is interesting, useful, or valuable. She stressed the importance of researchers revealing how their personal world influences their research (p. 6): "It is important to reveal not only more of the outer world on which we focus our gaze, but more about the inner worlds in which we assemble what we choose to say." A researcher's intelligent and intentional reflection on his or her experiences and emotional reactions to his or her research can ultimately prove beneficial to the research findings, and not doing so could be seen as dishonest (Gilbert, 2001).

The implication of this debate is not necessarily that inclusion of the researcher's self is appropriate in all types of research. I believe, however, that if the topic, research questions, and research design have very obviously and consciously evolved from the researcher's own life experiences, then the researcher should include as much about himself/herself as is relevant. Other researchers with personal experience with their topic have adopted a similar stance (e.g., Daly, 1992; Farnsworth, 1996; Kiesinger, 1995; Lauterbach, 1993). In the case of my research,

I would not have been exploring this topic without my personal experience of perinatal loss. I have struggled with the decision of how much of my personal experience to reveal and share. I have carefully considered the dilemma of using my experience yet not allowing it to cloud my interpretation of participants' stories (see "Ethical Issues" below). Like many others from Western cultures, I have always been a fairly private person, having difficulty sharing my most personal feelings and experiences with even my closest family and friends. As some of the above quotes from Krieger's book articulate, the thought of discussing my feelings of grief and other personal thoughts about the death of my baby has made me feel exposed, vulnerable, and somewhat "unscientific." As Krieger and others have pointed out, however, the richness of knowledge that can be created when researchers are willing to take that risk is something worth pursuing.

### 3.3 Method

#### *3.3.1 Participants*

I chose to limit this study to parents who had a perinatal loss. Most studies in this realm of research combine miscarriage, stillbirth, neonatal deaths, and even later infant losses as well (e.g., death by SIDS), based on the poorly supported assumption that these types of losses are equivalent. While I acknowledge that it is the degree of attachment to one's unborn child that determines a parent's intensity of grief, I believe that there are qualitative differences between these various types of pregnancy and infant loss. Just as perinatal loss should be considered separately from the loss of an older child, I argue that perinatal loss, miscarriage, and later infant losses should be studied separately in order to do justice to their unique presentations.

Second, participation was initially limited to individuals who experienced a perinatal loss at least one year prior to the interview date (with no upper limit on time since the loss). My rationale for this decision was that early grief has already been well studied, and I was more interested in the long-term processes of grief, meaning reconstruction, and self-changes. While the meaning-making and transforming process begins from the moment parents become aware of their loss, I was most interested in how their stories evolved over time. Some researchers (e.g., Boyle, 1997) have criticized studies that depend on retrospective recall of events, suggesting that the accuracy of such data is reduced (e.g., Rosenblatt's participants had losses that occurred as long as 46 years earlier). With a narrative methodology, however, I was more interested in how parents viewed their loss over time, rather than "accuracy" of their recall. That is, I was concerned with "narrative truth" (Spence, 1982) rather than striving toward an "exact reproduction" of the experience in a positivist sense (Blumenfeld-Jones, 1995). Indeed, the post-modern, constructivist underpinnings of a narrative method would suggest that a singular "truth"

or “reality” does not exist (particularly in the emotional realm of bereavement); that human beings continually construct and revise the meanings or “truths” of their experiences into a coherent understanding; and that concepts such as “accuracy” of a person’s memory of past events are therefore essentially meaningless. By privileging the individuals’ telling of their own lives, I am rallying against the traditional positivist view that people’s narratives are less preferable than the empirically-based accounts of the expert researcher (Gergen & Kaye, 1992).

In recruiting participants I included both men and women, and parents whose losses occurred recently as well as many years ago. Doing this is in keeping with a maximum variation sampling method (Patton, 1990), in which a broad range of information and perspectives on an experience is sought. For my purposes, this decision helped to achieve the goal of a depth of understanding of the diversity of experience and perspectives of parents. When selecting which participants’ stories to include for the full narrative chapters, my pre-stated intention was to choose participants with information-rich stories, or those with stories that did not fit with the “norm” as outlined by previous research (“extreme” cases; Patton, 1990). In practice, however, all of the participants’ stories fit these criteria in one respect or another. It was essentially an arbitrary choice as to which participants to include for the full narrative chapters, something I realized early on in the interviewing process. I was tempted to simply use a “first come, first serve” decision-making process, that is, to select the first 5 or 6 participants whom I interviewed. In the end, I did make the very difficult decision of which stories to present in full based on specific circumstances of their stories which would provide as diverse a picture of this form of bereavement as possible within the constraints of my stated goals.

Participants were recruited through a public service announcement, a newspaper column, and a newspaper ad (see Appendix A), as well as by word-of-mouth. The intention in recruiting participants through a variety of means was to avoid some of the problems of selection bias, as noted in bereavement studies whose participants are recruited solely from support groups (Leon, 1990). I discussed the study with 16 individuals from cities and towns in Saskatchewan who contacted me or were contacted via word-of-mouth sources. Interviews resulted from 12 of the 16 contacts, that is, from the 4 couples and 8 individuals who chose to participate in the study (see Table 1).<sup>9</sup> Of the 12 stories gathered, I chose only five stories to present as full narrative chapters, in order to maintain the richness and depth of the *lived*

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<sup>9</sup> Two of the couples had losses less than one year before the interview; I chose to interview them because they wanted to participate even after I explained the 1 year criterion for inclusion in the project. I informed them of my intention to write a book stemming from this dissertation, in which I hope to include

*experience* that is characteristic of narrative inquiry (e.g., Cherry, 1996; Kiesinger, 1995). Segments of the remaining seven stories have been included in order to reinforce and further highlight specific arguments, interpretations, and conclusions in the final two chapters.

Table 1. Summary of participants.

Participant(s)	Age at Interview	Time Since Loss
*Andrew	20	4 ½ years
Bill & Christine	Early 40s	4 months
*Deena	59	35 years
Irene	58	36 years
*Judi	47	26 years
Katrina & Luke	Mid 30s	7 months
Mona	Late 20s	14 months
Penny	Late 50s	30 & 25 years
Rachel	58	24 years
*Sharon	42	17 ½ years
Sonya & Owen	Late 30s	2 years
*Stacie & Dan	26 & 31	6 ½ years

\* stories selected for full narrative chapters

### 3.3.2 Interview Procedures

The tape-recorded interviews took place between December 2001 and May 2002. Upon initial telephone or e-mail contact, participants were sent an introductory description of the study (see Appendix B). They were offered the choice of having the interview at their home or at a location which I arranged. Seven of the individuals or couples chose to be interviewed in their homes, and five were interviewed in another location (either the Psychological Services Centre at the University of Saskatchewan, or an alternative suitable location in their city or town). All interviews were audio-taped and transcribed in full<sup>10</sup>. Before and after the interviews, and throughout the research process, I recorded my thoughts, emotional reactions, and impressions of the participants and the interview process to serve as a check on my interpretation of their stories. These notes also served as an additional source of data to be consulted during the

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their stories in full. I also informed them that I would include segments of their stories in this dissertation, as I deemed relevant when analyzing the data. They consented to proceed with this arrangement.

<sup>10</sup> See Appendix E for transcription codes, and Appendix G for a sample of a complete transcript.

analysis phase. Several participants chose to share mementos, poems, and photos during the interviews.

I started interviews by explaining the origins and purpose of my study, including a brief explanation of my personal experience with losing a baby (which they were aware of prior to contacting me initially). I informed participants of my general goals, such as understanding how they grieved for their baby, how they made sense of their experience, and how they felt they had been changed by it. A demographic information sheet (see Appendix C) was completed and participants were asked if they had any concerns or questions. Interviews were open-ended, with the goal of allowing participants to tell their stories in their own unique style and in their own words (McCracken, 1988). After the preliminary details, I asked participants to tell me the story of the loss of their babies, starting in whatever way they would like (Braun & Berg, 1994). In no instance did I have to follow this with additional questions or prompts because of participants appearing uncomfortable or unsure of how to proceed. This style of interviewing was adopted with the intention of minimising the influence of my preconceptions and expectations during the initial storytelling. An interview guideline (see Appendix D) was consulted only when participants needed prompting after telling their stories in full, and toward the end of the interview if I was uncertain that all relevant topics were addressed. If participants did not directly address the issues of meaning-making and personal transformations, I asked them to reflect on these processes at a point that seemed appropriate once they had an opportunity to tell their stories in an uninterrupted fashion. Interviews lasted between 1 ½ to 3 hours.

Unlike some qualitative researchers who have advised against using an “active listening” model (e.g., McCracken, 1988), I followed Kiesinger’s (1995) lead in “facilitating conversation” during the interviews. Kiesinger discussed creating a climate more akin to a conversation or free-flowing dialogue rather than an interview, in order to minimise the sense of the interviewer being in a position of dominance and authority in relation to the participant. Kiesinger suggested that this mode of interviewing allows participants to feel more secure and less vulnerable as they share their vivid and personal stories. This form of interviewing most closely resembles what Ellis and Berger (2003) called *reflexive dyadic interviewing*, in which the interview is conducted as a conversation between equals rather than a hierarchical researcher-interviewee model; the researcher is compelled to disclose aspects of his/her own experience because of the intimacy of the details being shared in the interview; and the researcher attempts to remain aware of (and later reflect on) interactively produced meanings and emotional dynamics within the interview.

Although participants were made aware of my personal experience with perinatal loss prior to contact and I willingly disclosed to all participants if they asked questions of me, I

purposefully limited how much of my personal experience I revealed in the initial part of the interviews. In studying anorexia and bulimia, Kiesinger (1995) used self-disclosure of her own experience of bulimia as a purposeful tactic that helped to create a climate in which participants felt comfortable enough to tell their own stories. These personal disclosures were quite brief at the opening of the interview, and were scattered throughout the interview process in order to encourage and support participants' storytelling. For my purposes, I was concerned with limiting my self-disclosure at the beginning of my interviews in order to minimise my influence on participants' having the opportunity to tell their stories in an uninterrupted fashion. In practice, I usually self-disclosed only when asked explicitly or implicitly (e.g., "I don't know what your experience was, but.."), while trying to remain aware of my impact on participants' storytelling choices. At times, I felt compelled to share my experience or my meanings that related to issues the participants appeared particularly unsure of (e.g., statements that implied, "I don't know if I'm abnormal in feeling this"). Frequently, participants would ask a brief question about my experience when speaking of a specific experience they had, and I would try to keep my answer short so as not to derail their train of thought. In most instances, they did not ask questions of me that required lengthy answers until they had told the core birth and death story.

At the end of the interviews, I shared a written copy of my story with my participants. As well, we discussed the possibility of engaging in a back-and-forth sharing of our responses to each others' stories, in written or verbal form (Tillmann-Healy & Kiesinger, 2001). Because of an overwhelming amount of data, this type of sharing occurred only to a limited degree with one couple and in depth with one individual (see Chapter 6, Sharon). Following the interview (within weeks in most cases), participants were given a smoothed narrative version of the transcript, with false starts, repetitions, and paralinguistic utterances removed to make it more readable. For those whose stories were chosen to be included in full, I provided them with my portrayal of their stories, and met with them in-person for a follow-up discussion and for them to provide me with their reactions and thoughts. These procedures were adopted to strive towards a richer and clarified understanding of participants' intended meanings and perspectives, and to serve as a check on my interpretation and presentation of their stories.

### *3.3.3 Analysis*

Polkinghorne (1995) categorised narrative inquiry into two distinct types: (1) analysis of narrative and (2) narrative analysis. In an analysis of narrative a researcher collects stories as data and analyses them with a paradigmatic process – that is, looking for general themes, principles, and categories in the narrative and applying a chosen philosophical and methodological approach (e.g., grounded theory, phenomenology, etc.). Narrative analysis, on

the other hand, involves creating a narrative that integrates and makes sense of multiple sources of data (some of which may be written or interview narratives). The latter was used in this study to analyse and present participants' stories. The final product of my analysis of parents' stories has taken the form of a narrative that incorporates some or all of the following: interview transcripts, my research process notes, reflections on my personal experiences and responses to participants' stories, and any feedback and other materials provided by participants (e.g., poetry, mementos).

The following discussion of the analysis procedures I adopted consists of two phases: analysing and interpreting the data; and writing an interpretive narrative that presents the analysis in a way that preserves the richness and intensity of participants' individual stories, as well as revealing a meaningful depth of understanding of perinatal loss as told by these parents.

#### *3.3.3.1 Analysing the Data*

As a way of approaching the data and forming initial interpretations, I used a "voice-centered relational" approach to reading and understanding the data, developed by a group of researchers at Harvard University Graduate School of Education (Brown, Debold, Tappan, & Gilligan, 1991; Brown, Tappan, Gilligan, Miller, & Argyris, 1989; Gilligan, Spencer, Weinberg, & Bertsch, 2003). I also followed adaptations of this approach as described by Mauthner and Doucet (1998). While it was rare for me to explicitly refer to the method or the "voices" in my interpretation of the stories (see chapter 9), this approach to the transcript data was the primary guide in how I came to interpret the stories and view the participants' attempts at meaning-making.

The voice-centred relational method was initially developed as an interpretive method for reading and analysing narratives of moral conflict and choice in young girls. Grounded in feminist theory, it emphasises the relational nature of research, specifying that research is a product of two or more people, the researcher and the researched (Way, 2001). The assumptions underlying this approach are that individuals are relational beings embedded in a larger social-relational context. Narratives are seen as revealing how individuals construct their perception of an experience – what they focus on as relevant issues, what they define as the primary conflicts, and how they decide to approach the experience. Further, the way an experience is viewed is dependent on the context the individual is embedded in – such as their relationships, the physical, cultural, and historical context, who is involved with them in the experience, and the individual's personal and cultural history. This method was therefore well-suited to studying narratives of perinatal loss to determine how parents understand their experience and the multitude of influences on their meaning-making process.



The voice-centered relational method involves four readings of the transcript: (1) reading for the overall plot of the story, including the context, the drama, the players, and so on. During this reading, the reader should also attempt to place herself, with her own history and experiences, in relation to the narrator – how she is responding emotionally and intellectually to the person, particularly if what is said does not resonate with her (Mauthner & Doucet, 1998); (2) reading for self and the voice of the “I” – listening for how the individual experiences, feels, and speaks about him/herself, by watching for use of pronouns (I, we, you). This allows for understanding how individuals speak about themselves before attempting to speak for them. The third and fourth readings involve listening for other relational voices that are relevant to the specific topic at hand. I followed Mauthner and Doucet’s (1998) approach to these readings, while remaining open to other additional “voices” that emerged from a close reading of the transcripts: (3) reading for relationships – listening for how individuals speak about their interpersonal relationships, both with close family and friends as well as the larger social networks they live and work in. This reading reveals how these relationships influence the individual’s perception of their experiences; (4) reading for the larger cultural and social structures in which individuals are embedded, in order to understand how these basic forces influence the individual’s process of making sense of his or her experiences. Finally, I added a fifth reading that focused more explicitly on identifying meanings individuals attached to their experiences and how they spoke of changes they underwent as a result of their experiences.

The actual procedures for conducting these readings involves using three different coloured pencils to mark each voice for readings 2-4. The first reading involves getting a general sense of the story, with notes being made about one’s reactions and so on. Using different coloured pencils on the same transcript copy provides the reader with a view of the multitude of voices without losing sight of the larger story and context. Once the visual representation of the latter three voices is achieved, it is recommended that worksheets be used to highlight relevant pieces of the text, and to make observations and interpretive comments. This step is important, as it is the first move away from the narrator’s actual words to the reader’s interpretation and summary of them (but still using direct quotes from the text). The final step involves answering a series of summary coding questions about how the reader understands the three voices.

The value of this approach is that it allows for viewing and staying close to the participants’ “multi-layered voices, views and perspectives rather than simply and quickly slotting their words into either our own ways of understanding the world or into the categories of the literature in our area” (Mauthner & Doucet, 1998, p. 130). Further, the reading for the individual’s voice of self is distinct from other qualitative research methods in that it preserves the



individual's processes of reflection and decision making, rather than focusing on general themes of action and interaction. As well, the method displays respect for the perspectives of the individual, while at the same time recognising (and guarding against) the inevitable and necessary role of the researcher's own voice and perspective in interpreting the stories. Finally, any consistencies and inconsistencies between the various voices reveals important information of the individual's ability to make sense of his or her experiences, which was particularly relevant in this study.

As a final step, in order to move from the holistic understanding of each individual to an understanding of the participants' stories as a whole, I identified common or universal themes that were especially salient across the 12 individuals' or couples' stories. This involved looking across participants' stories for recurring themes, sub-themes, metaphors, and symbols that connected individual stories to a shared social story (Mauthner & Doucet, 1998; Modell, 1992). While this procedure resulted in a "breaking up" of the individuals and their stories, it was an important step in achieving a sense of the data set as a whole and in adding a broader level of understanding of the experience of perinatal loss.

#### *3.3.3.2 Writing the Narrative of Participants' Stories*

Within a narrative inquiry, the process of writing a narrative that makes sense of the data analysis can be seen as an additional step in the analysis procedure. With this in mind, I used alternative writing techniques in an attempt to present the narrative data in a unique, provocative, and meaningful way that preserved the richness of the stories. Such alternative writing techniques also allowed for the inclusion of my own experiences, such that the reader can distinguish between my perspectives and those of participants.

My decision to present the parents' stories using such writing techniques was based on Kiesinger's (1995) dissertation on anorexia and bulimia. Kiesinger followed the lead of others who have experimented with alternative forms of presenting qualitative data (e.g., Cherry, 1996; Ellis & Bochner, 1992; Shostak, 1981; Ellis, 2004; Ellis & Berger, 2003). She presented her participants' stories as "evocative narratives," which are narratives constructed by her based on the multiple sources of information gathered, including her own personal experience with the topic at hand. Her narratives were constructed by manipulating voice and tense (e.g., using the present tense to draw readers into the experience); using scenes/episodes and dialogue between "actors" in the story; and writing in poetic form to move readers experientially through the text. For example, transcript excerpts might be presented in a poetic form that emphasises word repetitions or other particularities of language use that add to the impact of the conveyed message (see Richardson, 2003); or a first-person dialogue might be written that captures a

participant's verbatim story while also drawing in descriptions of the interview setting and the researcher's in-the-moment internal emotional responses. Kiesinger's constructed narratives were therefore based on the histories and experiences as told by participants, sometimes using their words directly, but other times using her own words in order to "tell a good story". Thus, at times transcript excerpts are presented essentially verbatim, while other parts of the narrative are constructed in a way that captures the essence and intended meaning of participants' stories, but in a form that also makes their entire stories come alive (more so than a transcript excerpt on its own can). Kiesinger recognized the importance of using self-reflection and other distancing and member-check techniques in order to ensure that her narrative constructions did not turn into fiction, or become solely a reflection of her own perspectives rather than those of her participants.

These writing techniques are obviously unconventional, even within a qualitative methodology that strives toward unique ways of understanding human experience. It is therefore important to comment on how I addressed the issue of trustworthiness of my analysis and presentation of results in light of using such techniques.

### 3.4 "Validity" Concerns in Qualitative Research

The issue of validity within qualitative research methods has been a contentious one, with much debate as to what criteria should be used to evaluate qualitative studies. A number of alternative criteria have been proposed based on the argument that because qualitative studies adopt epistemologies, philosophies, and methodologies that are very distinct from those of quantitative studies, they should not be measured with the same "ruler" (Becker, 1996). Here, I have described some of the proposed ways to evaluate qualitative research that are different from traditional quality control criteria, but serve a similar purpose. Criteria like these were adhered to in this study as appropriate.

Stiles (1993) proposed a number of ways of establishing the trustworthiness of interpretations based on qualitative data. *Triangulation* refers to gathering information from a multiplicity of data sources, methods, prior theories and interpretations, and then assessing convergence of the data across perspectives. Included in this is honouring the alternative interpretations that participants may have (e.g., getting participants' feedback on the analysis and interpretations and integrating it as appropriate). I addressed this criterion by incorporating participants' stories and feedback on my interpretations; participants' poetry and mementos; my own experience; as well as looking to previous theories, literature, and research. Another criterion, *uncovering* or *self-evidence* is established if the knowledge revealed through interpretation of the data provides a solution to the problem or concern that motivated the study.

To achieve this criterion, I have referred back to the existing literature and my research goals in my interpretation and conclusions. *Testimonial validity* is a means of comparing one's interpretations to participants' feedback on these interpretations. Finally, *catalytic validity* refers to whether the interpretation produces change or growth in the people it describes – how well it empowers and energises them. Such interpretations seem to resonate strongly with participants. I attempted to satisfy these two criteria by eliciting feedback from participants on my narrative reproductions of their stories.

Other researchers have proposed the need for criteria that are specific to narrative inquiry, as they believe this type of inquiry has unique characteristics in comparison to other qualitative approaches. Blumenfeld-Jones (1995) proposed the criterion of *fidelity*. Fidelity of a narrative inquiry refers to whether it portrays what a person's story meant for them, as opposed to "truth," which looks to the truth of the situation in a more objective (positivist) sense. Blumenfeld-Jones argued that narrative inquiry combines social science and a more aesthetic or artistic mode of representation. As researchers, we must find some way to satisfy the sometimes conflicting demands of these two orientations.

To achieve fidelity, I was mindful of the following suggestions made by Blumenfeld-Jones: First, the inquiry should acknowledge the *betweenness* or intersubjective bond between researcher and participant that influences the storytelling. At the same time, the larger social and historical context of the participant needs to be considered and preserved in the interpretations and in selecting salient data in the analysis. As well, there should be *believability* of the interpretation as being a reasonable portrayal of the participant's story, while also achieving *resonance* with the reader's experiences. Finally, researchers must be open and honest about the inevitable influence of their perspectives and experiences in the re-telling of participants' stories.

This last point is reminiscent of what others have termed *reflexivity*, which refers to actively exploring, recognising, and making clear in our writing how our own personal histories, subjectivities, and theoretical stances have influenced our interpretations of participants' stories (Marecek, Fine & Kidder, 2001; Mauthner & Doucet, 1998). Reflexivity is accomplished by documenting the data analysis process and the choices and decisions made, so that readers can judge for themselves what has been lost and what has been gained (Mauthner & Doucet, 1998). In terms of the present study, reflexivity was even more of a consideration because of my personal connection to the topic, as well as my use of unconventional writing methods. Clearly documenting my reactions, preconceptions, beliefs, and choices in how and what I wrote was

particularly important as a way of remaining true to participants' intended meanings while also "telling a good story."

### 3.5 Ethical Considerations

For those who are not familiar with bereavement studies, it may seem insensitive and unethical to ask bereaved persons about their grief experiences; the assumption is that bringing up the topic of their loss will invariably cause pain and sorrow, and that the potential benefits of the research do not outweigh the risk of inflicting pain on the participants.

There is, however, little or no evidence that this assumption is correct. Dyregrov (2004), for example, found that all parents in her interview study experienced participation as positive and did not regret participating. If anything, participants in bereavement studies have voiced their appreciation at having the opportunity to talk about their experience, even when they found it painful to do so (Dyregrov, 2004). This is especially true if it has been a number of years since their loss, because they seldom are asked to talk by those around them, and often feel they should not bring it up. As Cook (1995) articulated:

...one mother who recently participated in a bereavement study said to me, "Most people feel uncomfortable with my tears so I try to hold them back. It feels good to have my feelings accepted and not to have to apologize for crying." (p. 115)

Cook and Bosley (1995) investigated this issue further by sending questionnaires to bereaved individuals who had been part of a previous bereavement study. The majority of participants indicated that they found the interview process positive and not stressful, and those who found it stressful nonetheless found it positive. Several stated that they found it beneficial to talk about their conflicted feelings concerning the death and their loved one. The majority of participants mentioned personal qualities and listening skills when asked what the interviewer did or said that was most helpful, and that the interviewer was not embarrassed or uncomfortable with tears or emotion. A few mentioned they found it helpful that the interviewer acknowledged that she had also experienced the death of a loved one.

Dyregrov (2004) reported similar findings among bereaved parents, and emphasized the importance of adhering to bereaved parents' recommendations for researchers. Such recommendations included: being initially contacted through written form rather than telephone; being consulted on the location the interview is to take place and having input into the length of interviews; being met by an empathic and informed researcher who is sensitive to their experience; being taken care of before, during and after the interview, and having the opportunity to ask questions of the researcher; and being given the opportunity to discuss results, provide feedback, and receive a copy of the final report.

Rowling (1999) suggested that in bereavement research interviews there is a pull to use one's "therapist self," an instinct that must be closely monitored. The researcher must avoid engaging in therapy with participants within the interviews, although empathic listening is obviously important. Rowling suggested participation in bereavement studies gives participants a sense of power they normally would not have in a therapy situation. Rather than feeling powerful in a therapy context, individuals more often feel (at least temporarily) exposed, vulnerable, and in need of help. Rowling believed the sense of power derived from bereavement research interviews comes from participants offering their experiences so that other bereaved persons might be helped.

### *3.5.1 A Balancing Act: Benefits and Risks of a Researcher's Insider's Perspective*

My personal experience of perinatal loss has guided me at every stage in this project – formulating the research questions and designing the study, conducting the interviews, analysing the data, and writing the final document. Farnsworth (1996) discussed the potential benefits of having personal experience with one's research topic. In her study of maternal bereavement she found that participants were relieved to share their feelings and stories with a researcher who was also a bereaved mother. They reported they would have been cautious and less open with someone who might not understand the pain of parental bereavement. Such personal experience, however, simultaneously presents challenges to the conduct of the research.

Like any researcher, those with an "insider's perspective" approach their topic with predetermined expectations and assumptions. Insiders, however, have a taken-for-granted reality that presents a potentially greater challenge to their ability to recognize when their own "voices" are drowning out those of their participants (Daly, 1992). Daly suggested that this tendency can play itself out in terms of overlooking certain aspects of participants' perspectives, and assuming familiarity when the participants' realities are in fact quite distinct from those of the researcher. Daly recommended that researchers therefore "manufacture distance" (McCracken, 1988) by actively finding ways to view the issues from a different perspective. In essence, researchers with an insider's perspective must strictly adhere to the principles of self-reflection and openness about choices made throughout the research process, possibly even more so than other qualitative researchers (Edwards & Ribbens, 1998). This is necessary not only to ensure that the findings of a study are credible, but also to protect and display respect for participants' realities.

A further ethical challenge is that researchers with an insider's perspective must be aware of the personal risks to themselves that could potentially affect the research process. This

research has presented risks to my emotional well-being on occasion. At times it has been difficult to distinguish my research from my own continuing grief:

My grief and my research have become one. I can no longer separate my “true” feelings of grief from those triggered by my research (journal entry, July 2001).

I don't take as much comfort in the pain now as I did for most of the past 2 ½ years. Sometimes I do, but it's not as certain now which I will feel when the pain surfaces – peace and comfort, or agony and a desire to push it all down again. Maybe part of the reason for wanting to push it away is that I haven't fully processed the pain of my participants yet. Like my own grief, I cannot just hear theirs and walk away without thinking about it and feeling it again. (journal entry, May 2002)

Dear parents: I listen to you talk... in person, on tape, on paper; and I hear your pain, I feel your pain, and I feel my own pain again. Over and over my pain surfaces, triggered by a word, a phrase, your tears... I often wonder why I'm doing this to myself – does anyone understand how difficult this is? You seem to understand, and you have thanked me for what I am trying to do. Thank you for recognizing what I am going through. (journal entry, May 2002)

Tillmann-Healy and Kiesinger (2001) pointed out that a researcher with personal experience with her topic can also experience a troubling dissonance when encountering aspects of participants' stories that do not fit with her own experience. They suggested that this can cause the researcher to experience a “sense-making crisis,” inducing the researcher to question her previous understandings of her own experience<sup>11</sup>. Because of issues like these, it was particularly important for me to continue to reflect on and reveal my reactions and emotions in order to balance the risks and benefits of this study for myself and for my participants. Being open and willing to reach out for external support from my research group, friends, family, and my research supervisor was also important throughout the process.

On the other hand, researchers with an insider's perspective with the topic being studied should also be open about their personal motivations and the potential benefits *to them* of engaging in the research. Bernstein (1998), a parental bereavement researcher who is also a bereaved mother, articulated what she believed to be the reason she did her study of parent's grief:

When we meet other bereaved parents, we're home – with people who know that language and who understand the subtleties foreigners can never truly know... Ultimately, I think that need for bonding, the need to come home to a familiar place, is what motivated so many people to volunteer to be interviewed. Looking back, I now think that the need to bond with other bereaved parents was one of the factors that impelled me to begin this project. I learned a great deal from the parents I interviewed. (p. xxi)

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<sup>11</sup> I experienced a mild form of this in working with Sharon (see chapter 6 and “Sharon's Meanings” in chapter 9).

Like Bernstein, it is likely that one of my indirect motivations in doing this study was to have the opportunity to interact with other parents with experiences similar to mine. Such interaction was personally therapeutic at times, and it inevitably influenced my own search for meaning in my experience. Mid-way through the recruiting process, I wrote:

...how many more parents will reach out, wanting to tell their stories, eager to help others as well as themselves through the telling? And me. They help me too... I feel their strength, for they are survivors, as I am... (journal entry, February 2002)



In the five chapters that follow, five of the parents I interviewed tell their stories with a degree of openness, honesty, insight, strength, and wisdom that has humbled and inspired me. Their stories speak not only to the specific issues of perinatal loss, but to what it means to be human, to endure losses that cannot be made sense of, and to survive and learn to live again.



#### 4. DEENA

*Today should have been my first celebration of Mother's Day  
I would have done my best to be a good mommy to you  
But since you've been gone  
I don't think other people consider me a mommy  
So there are no Mother's Day cards  
Just another quiet day without you*

*I am left alone to search for things to remember you by  
I can't give you Christmas or birthday presents  
So I search for angels, ornaments, poems...  
Anything to show the world, and myself,  
That you existed, that I had a son  
To make people remember  
That I am a mother  
Even though I didn't have the chance  
To mother you outside of my womb  
For even a moment.  
I would have been so proud  
To show you off to the world*

*~ Myrna (May 2000)*



Deena's involvement in this project came about through her niece, Kim, who heard about the study and immediately thought of her aunt. Through initial discussions with Kim I learned that Deena had lost a baby shortly after birth. Kim also mentioned that her aunt has had an ongoing battle with depression. Deena's first response when I spoke to her was that she would like to help out but she was unsure that she remembered enough or could contribute anything worthwhile. This tendency to view herself and her contribution as less than valuable remained evident during our interview. She was valuable to say the least, as was her contribution. Her story has touched and moved me deeply. I have related to her on many levels, but especially her experience of being a "childless mother," a status that I shared with her for the first 4 years after my son's death.

Deena was 25 years old in 1967 when her son Shawn, her first baby, died when he was 4 days old. At the time of our interview the 35<sup>th</sup> anniversary of his death was days away. She had two miscarriages in the years following her son's death, and her 9 year marriage ended some time after that. She had been married to her second husband for 27 years at the time of



the interview, with whom she has a number of step-children, step-grandchildren, and step-great-grandchildren. She had no other children of her own.

§

*My heart and thoughts race as I wait at yet another red light on the way to Kim's house, where Deena's interview is to take place. After conducting and transcribing two other interviews I am questioning my interviewing skills, and I'm concerned that my personal experience is affecting the questions I ask and the comments that I make. This is my first interview with someone whose loss occurred many years ago. What if she doesn't have much to tell me, or tells me that it is something she "got over" years ago? Or what if I do more harm than good by asking her to talk about this experience, especially given her struggle with depression over the years? As I pull up to the house I take a deep breath and decide that like myself, she is likely not that fragile, and this may actually be helpful for her.*

*Deena greets me at the door and invites me to sit at the kitchen table, where her elderly mother is also sitting. We chat for a few minutes as Deena gets coffee and I set up my equipment, and then her mother excuses herself so that we can get started. A fleeting thought passes through my mind that at some point it would be good to get other family members' perspectives on perinatal loss. I'm sure that Deena's mother has memories and feelings about the loss of her grandchild and the experience her daughter went through. I snap myself out of this thought, reminding myself that I'm feeling overwhelmed with what I'm faced with as it is.*

*I start off by explaining to Deena my reasons for doing this study, and I speak generally about the broad research questions I'm seeking to answer. She listens politely, but has no questions. I sense that she is perhaps nervous about telling her story, but there is an eagerness that comes forth as she begins to speak as well. I realize that this might be the first time she has had the opportunity to talk about her experience since it occurred 35 years ago. This thought saddens me, yet I feel honoured to be able to hear her story in this kind of depth.*

§

Well, this was from a previous marriage, and actually, he would have been 35 now, on the 17th of February. So I always compare him to my nephew, John. They're just about the same age. And I compare, that if he would be living, how he would be today, what would he be like? You keep thinking these things.

I had a very hard labour. I had an old doctor, he was very, very old. And he never had any consideration for his patients, he was kind of abrupt. He never came until the very last, and then they used so many instruments on the baby that he got so bruised, his whole face was bruised and his whole back and everything. But he lived for 4 days, and I named him Shawn

Allan. They didn't know at first that he was really sick! They just thought he'd been bruised from the instruments. He seemed healthy to me, but wherever I burped him – after he had nursed – wherever I patted him he turned blue. I found out later it was because he was haemorrhaging inside. And he was just.. he was all marked. And, of course, when he first came like that, and I.. well I was.. really dumb about everything, but I kept on saying, "What's wrong with him?! Why is he so bruised, and why is he bruising more?" "Oh that's just normal," they would say, and the doctor would just say it was nothing.

And then on Monday – he was born on Friday morning early – and on Monday they came to me, I was breast-feeding him and they came and they said I couldn't have him! They would feed him themselves. They didn't tell me why. And of course, I was by myself, my husband was very cold to the idea, he never even saw the baby, he didn't want to see the baby. He just didn't go and see him! He was very.. different. And I don't know what he felt, he wouldn't tell me how he felt. He never did say anything, he just kind of blamed me for the death, afterwards. If anything came up about it, I never had any chance to talk to him about it, because if I said anything, then he would just get mad and he would start swearing and calling the baby names and stuff.

On Monday they came back to me and they said that my baby was very sick, and of course they didn't tell me what was wrong, but they said they'd phoned different doctors in another city to see if they could get some help for him. And then they finally came to me at about 2 I guess, 2, maybe 3 o'clock in the afternoon, and they said that he was bleeding from the liver into the abdomen, and there was no way they could stop it. And so they let me go and see him. He was in the incubator and he had tubes in his feet, in his poor little feet and arms, and he was just.. laying there, as white as a sheet of paper, because he just.. was draining all the blood out. And.. I was in Hospital X where the Sisters worked. The Sisters were good, and the head nurse was very good. She was comforting. But they didn't say much, you know. But the Sisters came to me and they said – without my permission, but they knew he wasn't going to live – they said that they baptised him. So he was baptised, because they knew that he wasn't going to live. I didn't have anything to do with it, but he was baptised anyway. And it wasn't my religion, but it was good that they did it, I thought. I'm happy they did that, because I have that feeling, you know, I have that knowing, now, that he was baptised.

I phoned home, but back then we never had telephones, not everybody had telephones. So I had to phone the neighbours, which was about 3 ½ miles from my mom's place, and get them to go down and catch my dad, so that he could run and tell my husband that the baby was sick. By the time my husband and my mom came to the hospital, the baby was gone. And of

course, I was really taking it hard and my mom was a good comfort, but my husband wasn't. He seemed so cold... At that time you really feel like you're lost. You just don't know *why*? You don't understand why it should be. And the doctor came and saw me, and he said that they were treating it like a haemophiliac. But I just don't believe it, because it's not in either families, it's just something that you've never heard about, well, I mean I've heard about it, but it's something that... I'm sure he was injured from all the instruments during delivery. I should have had a Caesarean, but back then, they didn't do things like that very often. It's quite awhile ago.

And of course, the doctor was old, and he never had any compassion. I can remember crying and crying, and he never said he was sorry really, or anything. And he just said to me, "Oh well, you're young yet, you can have more." But that didn't help me! I never did have any more, because I had two miscarriages after. So it was just not meant to be to have children, I guess. I don't know, maybe because my marriage wasn't going to work out, or what. I'm quite religious, and when I think about it, I think well, God maybe could see further ahead than I could. And maybe it wasn't meant to be.

That night after the baby had passed away I said to the doctor, when he came I said, "Well, I don't want to stay in here anymore," because I was in a room with 3 other ladies and they all had babies brought to them, and I wouldn't get mine. And I didn't want to stay in that room and see that. So I said to the doctor that I wanted to go home! And he said, "Well the only way you can go home is if you stay in the city, because you can't go out any further in case you start haemorrhaging." And so my husband's sister said I could come and stay with her, and my mom could come with me. So my mom and I stayed with her for about three days I guess, until I was well enough to be able to go home.

My brother came in and we went down to the funeral home and made the arrangements. We did have a funeral, but only because of help from my brother and my family, because my husband wouldn't come with me to even look at the baby in the funeral home. I had my brother do all the arrangements. We had the funeral in town, in the church in town. He just had a small white casket, just a very small casket. And just the funeral home director carried it, because there didn't need to be pallbearers or anything. But we did have a real.. a church funeral. And the neighbours were good, in the respect that they took up a collection, and gave us some money to help pay for the expenses. Because back then, although it didn't cost very much, I think it was \$100 or something, but it was hard to get money back then. We were just farming, so there wasn't that much coming in. After the funeral, he was buried where we lived, where I lived when I was first married, because the cemetery was on our land, only about ½ a mile away. We buried him there, in the cemetery.

I have pictures of him that some people took while he was in the casket. I have that, and I have his book from the funeral home. But I still remember what he looked like, and I can still remember him.. you know, in that little bundle when he came. I'll never forget the morning that he was born, after he was born I felt good! Sure, I was sore and stitched and everything, but I felt pretty good, and I was hungry, because I hadn't eaten for days. And so I asked the nurse if I could have some toast and milk, or coffee, or something to drink, and they brought me some, and I just drank it and I threw it right back up again! I thought I felt good, but I guess I wasn't!

When I returned home I had the baby things, and that was very hard because you have to put them away again, and get them all done up. I did it myself, I liked to do that myself rather than have someone else do it for me before my return home. And I kept the things for a long time, because I thought, well.. maybe, you know, some day you'd.. get to use it or something.

In the years that followed, I had two miscarriages. I spent Christmas in the hospital one year because of a miscarriage. I was about 3 ½, 4 months pregnant with the first one, and then the second one was about 2 ½ months. The first one really... kind of hurt a lot, because it was further along. And I... I was so-o.. naïve back then. Like now, I think of all the questions I would have wanted to ask the doctor. Because I had a good doctor then, I had a very good doctor. And I could have asked him anything. But I.. I was just so.. dumb, I just... you know, I don't even know if it was a boy or a girl, and they could have told me if I had asked. But they didn't volunteer those answers at that time. I keep thinking that... well, if that one would have lived – and maybe it was a girl, I don't know – but then it would have been the same age as my niece, Kim. And again, I compare, and wonder what that baby would have been like.

§

*As Deena has told me these details of her baby's life and death and her 2 miscarriages, I have noticed her face flush and her eyes well up a number of times, as have mine. Yet she has not cried, despite the obvious emotion she has been feeling. I wonder at the depth of emotion that she has kept to herself for so many years. My comments and questions in the past several minutes have suggested my reaction – anger and sadness at the way she was treated by her husband, the lack of support from her doctor, and the inevitable problems and oversights made because of the time period during which her son was born. As I mull over my own feelings about her experience, Deena goes on to tell me about her ongoing feelings of grief.*

*"But um... I still.. I still feel that ache in my heart that.. you know, you wish you could have had... **someone**"<sup>12</sup>. You know, even if it was just the one. Especially when you carry him for 9 months, and you've gone through~...But ah..."*

*"You develop that.. bond pretty early, yeah," I say, feeling the familiar ache in my heart that she has just spoken of.*

*"Yeah, yeah.. you know all about it, yeah." Deena seems to sense that there are some things that don't need to be expanded on as she speaks to me. Perhaps she feels more comfortable talking to me than to someone who has not 'been there'? I hope that this is the case, and that I can provide her that much comfort at least. Deena and I sip our coffee, taking a break from our emotion-laden discussion.*

*"And right now, his.. the.. the.. like my ex-husband, he died too, so he's buried there, beside the baby. And I have feelings about that too, because, um... why? He didn't want nothing to do with the baby before, you know, why didn't he go where his mom and dad are?" Deena laughs softly as she says this, camouflaging her anger at this turn of events.*

*"Did he make that decision himself, before, or~?" I can only imagine the added pain of having to sit beside her ex-husband's grave as she visits her son's.*

*"Well I don't know if he did or not, you know, I never, I never... we divorced many years ago, and I've been married to my second husband for 20--, 27 years last January. And he's wonderful, so..."*

*"So you must have a lot of anger around the way he~" I grope for words to express how she must have felt about her ex-husband's response to their son's death and to her grief.*

*"A lot of anger, yeah, because I had no one, like.. I lived--, we never had power or running water or nothing, we just had to, you know, do everything, the old way. And ah.. I tried hard... to.. to cope with it, but there was nobody to.. talk to really. I talked to my mom and my dad a little bit, and my brother, of course, he was good. And Joan, Kim's mom. But.. still.. you know if you could have talked to your husband about it, and if he would have.. understood a little bit more, the feeling you were going through, because.. I think a mother is--, when you go through that, you really.. bond fast, and you just... can't believe it."*

*"Mmhhh, yeah. So, so then you didn't get--, I mean, you didn't just **not** get support from him, you, you were also.. abused in a way?" I instantly regret putting words in her mouth, but I want to pursue this further, feeling both distressed by how Deena was treated by her ex-husband and curious about his reaction to his son's death.*

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<sup>12</sup> Note that words that are emphasized throughout the stories (italicized, bolded, underlined) represent

*"I was--, yes I was, because, um.. I know that, like, I wanted to have a cover for his grave.. and ah.. for my baby's grave. And ah.. I worked, I was working outside the home. And I said, well I was going to pay for it. But the guy that was doing it for me said that he'd do it on payments, like I could just give him payments, you know, every month, or however I wanted to do it, and I could pay for it. And.. one time my husband got the mail and he opened my letter, and he threw it at me and he said 'Pay your goddamn bastard's bill!'... And that just hurt so bad, because he wasn't~ He didn't have any right to say that." Deena shifts from anger to a profoundly sad voice as she relates this story. "And that really hurt. So.. that's the way he treated me, like he was, he was.. he was an alcoholic, he turned out to be an alcoholic, after. So ah...when we were first married he was pretty good, but it seemed like, I don't know, it changed. Maybe--, I know he told one of the neighbours that maybe it would have been better if the baby would have lived. Things would have gone better for us. But I.. I don't know, because.. maybe.." She trails off, not sounding convinced that things would have been better in their marriage.*

*"Was he--, ..so he became like that after.. after the baby died? He wasn't mean before?" I am intrigued by this hurtful and rather sudden change, which Deena can only speculate about of course.*

*"He wasn't that bad before, no. He just kind of... resented me, I think.. for--, and I mean, blamed me, I think, for my part in it, and~"*

*"mmm, yeah.. as if you had any part in it. You had no control over it." My anger at her ex-husband resurfaces, replacing the moment of sympathy I had for him.*

*"Yeah. I had no control, no, I..."*

*"That's just the way he.. dealt with it I guess.. or didn't deal with it."*

*"I guess so, yeah, yeah, so ah..."*

*"That was.. awful, I mean, very hurtful~"*

*"It was very hard, for me. And.. like, to go home.. I stayed with my mom for a little while, my mom and dad. And then to go home.. um.. I was all alone."*

*Since there is no way that either of us can understand what was going through her ex-husband's mind and heart, I continue to listen and seek further information about Deena's grief after her son's death.*

*8*

*I don't do anything to mark special occasion days like Christmas, his birthday, or the anniversary of his death. But I always.. I know it, I always remember it. And I think, when it starts*

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actual emphases from the interview transcripts.



coming closer, I can remember... it was the 15th when I went into labour.. and all this kind of stuff, and.. what you went through, and... At this time of year, the anniversary of his birth and death, I think I'm a little more sensitive maybe. You know, when you think of it, like it all happened at this time.. 35 years ago, you know. So... it's a long time ago....

It feels better now than it used to. It feels better. I think I've learned to live with it. I mean I... I don't resent it... as bad, I don't think, as when I lost him and I.. didn't know what really to do, you know. I felt so bad, and there wasn't anything.. anywhere to go for help. And what I got, when I first came home, was, "Oh well, go ahead and have another baby right away." "That's the only way to get over it," I was told. Well... for me it wasn't. Sure, you can have another child, but it's not the same as the one you had! They're all.. special. You have the same feeling as if they would have been older when they'd gone, because you held them, you had them.. you carried them for all that time.

I think of the baby a lot. I do, especially when I see babies. Then I think, well.. I had my own, but... Especially, people will talk nowadays – the younger moms – about what they went through and stuff. Well, I went through it too, but nobody realises that I did. Over the years, my mom is the only one to bring up the topic a little bit. She will often mention if Shawn would have lived, maybe he would have been this or that, or different things. Especially when he was littler, when he would have been smaller, then she says, well she would have been babysitting him, things like that. She was good. That was helpful, to know that at least one other person remembered what I went through.

I think the biggest part, a lot of it is that I feel that people don't think I went through anything. I even feel that way with my miscarriages, because I never had any grieving period then at all. Nobody acknowledged it. It was just something that happened, and you were supposed to forget about it. Everybody else forgot, but I didn't. It was just something that happened and.... you were supposed to get over it and keep on going. And that's mainly what I did, you know, I worked, and so you kind of got back into your routine again and kind of tried to push it at the back of your mind, and go on. You wonder if there's something wrong with yourself, you know. You really wonder why you feel this way, and the others don't even think about it, you know. Because ah... never mentioned.. I don't think anybody ever mentioned anything about my miscarriages to me. All that was said was to just try again. And to me that was, you know, right then.. that's about the last thing you want to hear, because... you wanted that baby.

When people ask if I have children I usually say no, unless it's a doctor or something, then I just usually say, "No I haven't, but I had... and I lost them." I include the miscarried babies



too, because they were a start of a family too. If others ask, I usually just say, “No, I have step-children,” because I have 4 grown step-children from my second marriage. And they’re all wonderful kids and we’re pretty close. They were all grown up when we got married, they were on their own. But they’ve all accepted me well. They always – when I invite them, or even when I don’t invite them – they come to see me, to visit. And they’re good to me. And my grandchildren are good. They’re all very good. Especially, I have two that are right in the yard, they’re grown now, but they call me Grandma. And they’re very close to me because I’ve been their grandma ever since they were born. And there’s the others that are older, and they will say, “This is Grandma Deena,” or something like that. And I’m Grandma to the kids, to the great-grandchildren, they call me Grandma.

It’s nice that way, that I’ve got grandchildren, and great-grandchildren, little ones around. But I still think back, when I.. when I see babies, and.. when I hold them.. that I~.. you know... There are many questions you ask, like, “Why? Why was it me?” You know... had he have lived, would he have been okay? Or would he have been a sick baby? Maybe there was something else wrong that back then, the doctors didn’t know. Maybe. Maybe, I mean with all the tools they used, or the forceps and stuff, maybe he had brain damage. Who knows? You know.... you wonder. Maybe I could have done something more for him, I don’t know. But it--, my hands were tied. In a way, I blame myself. I wonder if I.. if I would have noticed it more? If I would have paid more attention to him, sooner? But I.. I don’t know. There isn’t anything you can do.

I wouldn’t say that I’m at peace with those kinds of thoughts. I have never really said.. that I could forget it. I still think about it. But I think if I could have.. talked it out more... Even back then, if you could have had a counsellor, it would have helped a lot, to go. Later on I had talked to counsellors about things like that and different things, because my nerves are bad. And I had depression, and some of it I think relates back, maybe, to some of that part too. Because... you carry it with you for so long, and finally it comes out a little bit. You can’t keep it under control all the time, it’s in the back of your mind I guess.

82

*I can't remember that I really grieved that much  
Not openly  
I kind of put it in the back of my mind  
because I couldn't talk about it to anybody  
or to that many  
And everybody shut up.  
They never.. questioned me about anything  
they never asked me..  
how I felt  
or anything about my feelings.*

*It was just kind of like..  
it's all over...  
That's it, the door's shut.  
But it's not.  
Not to the one that's gone through it.*

8

Even now, I think... I feel that the people around me at the time could've been.. everyone could have been a little bit more thoughtful, you know... Nobody came to visit, really. They just.... kind of let me be on my own. But now, you know, it doesn't hurt so much as it did back then, because it was so new and everything. Kind of learned to.. to live with it now. But I guess... maybe people thought I couldn't talk about it. I was even a little surprised with Kim, when she had me do this project, because I didn't think that knowing that I had a baby really... mattered that much to her? Like I've never spoken to her about it either. I thought it was kind of neat, it was kind of nice that she would think of me, and suggest that I do this because... otherwise, you know, you feel kind of shut out. You feel away from the world, or kind of that you had a part of it but no one else thinks you did.

I guess this has no bearing on what you're asking me, but we lost three grandchildren, all at one time in 1986, and ah.... just.. like the feeling that I went through then... They were all killed in a car accident... And it brought back, a lot of feeling about me losing the baby. Like I really... grieved for them. And ah.. I think I grieved more because I had had a baby and lost him. And at that time, my step-daughter that lost the two girls said to me, "Well, you know what it's like, don't you?" And I said, "Yes, I do." I felt good about that, that she could talk to me and recognize that I also lost a child. It made me feel good, that we could talk about our losses, and stuff. But that was, you know, quite a long time afterward. Quite a bit of time had gone then...

When anyone close to me dies now, I think it's more.... like notice it more, or you feel it more? Because.. ah..... especially when my brother passed away 7 years ago. I really~.. And I didn't... have the time to grieve for him like I should have either, because I had to take over his job right away. And ah.. I had to keep my mind on all my other things to do, without... just grieving for him, you know, because I had to take over his job. And that was hard. To take over his job. But ah.. for close people, I think that I.. I do feel it more. I think my grief over the baby comes back then. It brings it all back, sort of, what you went through. You know.. when he was... when you had to.. make up the plans for the.. funeral, and everything. It all comes back. Even though so many years have passed, the memories are all there. You still remember what he looked liked, and.. I can still remember him... in that little bundle when he came.

I have noticed some changes in myself that are because of losing the baby. I think I'm more sensitive to kids. Like I think about... little kids more. I'm more sensitive to people's feelings

maybe? Because I feel I was... kind of neglected, you know? And I kind of think of people that go through something like that, I think they should be shown a little bit of... compassion, more compassion. I know when our grandchildren died, my stepdaughter's husband didn't want to talk about it either. And she had an awful time with that, which I can't blame. So we talked a lot, her and I. Because I wanted to talk, I wanted to talk as well as she wanted to talk. And I wasn't going through exactly what she went through, because she lost two. And they were teenagers. But.... I still had gone through it. So we could talk about it, you know.

When people talk about pregnancy and childbirth, then I feel.. what I went through. Like I go through it again, sort of thing. But I never ever say anything to them about it. I never say, "Well hey, you know, I had a baby too," or anything. Just... if they're talking about it I just really don't say anything. But I'd like to. That's normal I think, too. Because you have that feeling, well, you were a mom too. Like my daughter-in-law that lives in the yard with me, she and I went to the city one time, and she had just the little one then, the little girl. And we left her at home. And my daughter-in-law saw a baby in the mall, and she said, "Well I've got one too, like that, mine's at home." And I felt like saying, "Well, gee, I had one like that too," but I didn't... I still feel like I want other people to know about the baby sometimes. I'd like to say, "Hey, you know, I had a baby, and he would have been so-and-so old now," and, you know... I feel that way sometimes. Especially if people are talking about their kids. You know, and you sit there and you... you don't say anything because you... haven't anybody that's living to talk about, to compare to their kids.

In my mind, I compare him and the first miscarried baby to my nephew and niece, John and Kim. I mean, Kim and John are like.. my kids. I'm pretty proud of them. You're always... you think, well, would he be as talented, or would he have turned out as good as these kids did, and you wonder... what kind of a background, if he would have been involved more with his dad, or if he would have taken after him. You don't know these things. It's something that you just ask, and.. sort of stays in the back of your mind.

§

*Myrna & Jacob: I sit by the playhouse that would have been yours, and I think of you... how you would be over 2 ½ years old now, if you had lived. Maybe you would play in the sandbox with your daddy's old toys. Or maybe you would slide down the bright yellow slide with joy and excitement on your face, and total trust that I would catch you at the end...*

*My fantasy is interrupted suddenly by a hummingbird zipping by overhead and hovering to feed from the honeysuckle nearby. My thoughts are a million miles away, unable to be warmed or comforted by the sun and the natural beauty around me. I could have been the mother of a 2 ½ year old now. A wave of grief passes over me as I mourn my lost motherhood. I*

*think back to a lunch conversation the other day with some friends who have children. Listening to other mothers talk about their parenting dilemmas makes me think about my own lack of opportunity to parent Jacob. I wish I could get in on the conversation, but talking about my experience of being a mother to a baby who died just wouldn't fit, somehow.*

*I'm keenly aware of children who are 2 ½ to 3, especially ones whose mothers' I had some form of contact with when I was pregnant. I've seen some of these children for the first time in the past couple of months. It's shocking to me that they're talking, thinking, active little people and not babies anymore. Jacob is stuck in infancy in my mind, and seeing these children makes me long more and more for an image of him at the age he would have been. Even my fantasies contain pain though, because of the intruding thought that Jacob would have died anyway, if he'd been born alive, because of the severity of his birth defects. But maybe for a moment I'll allow myself to imagine him running in the yard, eating ice cream, or riding carefree on his dad's shoulders as we stroll down the road...*

§

I marked the anniversary of his death once by putting the date in a calendar one year. In a neighbouring town, they put out a calendar for families to put all the dates on there with anniversaries and birthdays and stuff like that. Or in memory. And I put his name in there, in memory. I put the name there that year. I figured, well, if people would read it, they might want to... they might realize... It is kind of a hard feeling, thinking that people don't remember him. Because ah... it feels like he was never... to some other people he was never here, like he was, you know, he was~..... I don't know... that I never had any.. children. Because I have nothing to show.

I don't know why I'm kind of scared to talk about it to anyone, because it is.. true, it has all happened. But... it's just that you have no one to show... nothing to show for it, what you've gone through, really. You don't know how to go around to bring it up really, unless they approach the subject, and they're not too likely to approach it when they don't know your history. There's lots of people that have gone through this type of loss, and lots a person doesn't know about. Because they don't talk about it. You don't know how to bring up the subject, really, because it's something that's passed. I feel like if I bring up the topic, other people will think, "Aghh, that's just so far away, why is she even thinking about that! She never went through anything, she never raised any babies or any children."

§

When I see babies  
Then I think, well...  
I had my own...  
but nobody realises I did.  
They don't really.. understand  
there is still that feeling of...  
of having a baby  
and being a mom.  
But you're not in the same group, really  
not in the clan

§

### The Gravesite

I certainly am happy that we had a funeral. And I'm glad I have the pictures too. They're just black and white pictures because you didn't have colour back then, but they're just as good as anything else. I don't have a lot, but I have about three of them I think. And ah... you can still see him that way, you know. And I go to the grave, I go once or so a year.

But.... I don't feel as good to go now, with his dad's grave next to his. I feel... I have a resentment for that. Because his family could have asked me, too, what I thought. He didn't want anything to do with the baby in the first place. I think his family could have asked, but they... most of them won't speak to me. Well, I shouldn't say most of them, but half of them or so. They're very bitter. And.... some of them are good, but.. ah.. I guess it was their wish, or his wish, I don't know what. It would have been nice to have my wishes... considered too. I just feel like, when you're going there, I'm not going to pay respects to him, I want to pay it to my baby. You know, and he's right, there... It's hard. But that's something I've got to... try to get off my mind, in a way, because it's not going to change, it's going to be there. It's just that, you have that little resentment there about it. I have thought about having his grave moved, but then I've thought, well... I guess it doesn't really matter where he is. But I did think of it, that I would someday move him to where my dad is. I don't imagine it will ever be, but... I have thought about it. I never did, until they put the.. my ex there, and then I thought it would have been nice if he could have been away from there. But I guess I'm just bitter. I shouldn't feel that way, but I just... One thing I know is that I don't go as often as I should. You know, to the grave. Well I don't know if... as often as I should, but as often as I did, I should say, before, when he was by himself there.

I think it's very unfortunate that they buried my ex-husband there. Because that's not the cemetery that his mom and dad are at or anything, and that was not his belief, really, that church's cemetery. He should have been in the other one, I feel, but then... I'm not to say. I guess I can't... condemn somebody else.... I just feel that way, and I have shared that with my

stepdaughters, that I feel that way. They feel, too, that I should have been able to have some say in it. Because it.. it was my child too, that was there. And I'm the one who cared, or showed that I cared, and he didn't. And he didn't. He didn't want anything to do with him..... But ah... I guess they never even.. maybe they never even thought about it, but.... I think I should have had a little bit of say in it, you know..... I don't know....

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*Over the past hour, Deena has asked a number of questions about my experience, showing both compassion and interest, probably more so because she has not had many opportunities to speak to other bereaved mothers. She has been particularly interested in the level of support that I received from those around me. After talking about her ex-husband and the situation with his burial next to Shawn's grave, she has another question for me.*

*"Did your husband, was he good, was he a good.. support?"*

*I feel somewhat guilty as I respond, since this aspect of our experiences is very different, and I wish she could have had a more supportive husband, as I have. "He, he was good, yeah. He's been.. he's been good. He's often not wanting to talk about it, but.. he'll listen to me. He doesn't talk about himself, but he listens."*

*"Oh yeah, well that's good." Deena takes a sip of coffee. She sounds sincere as she says this, but there is also sorrow and bitterness in her tone. My sorrow and anger at her ex-husband's response resurfaces. "So yeah, but that's just.. awful what you had to... what you faced. I can't imagine that."*

*"Yeah, it was--, I guess.. um..." Deena sighs audibly, struggling for words. "It was hard... not to have.. a support from him... Because, it was, you know, there's another thing too, like, with the cemetery now, with my baby there, um... where am I going?... I, I don't know if I would have went there anyway, because I want to be where my husband will be buried. But ah.. I wouldn't go there now.. for sure... 'cause.. I just.. I just wouldn't." Deena speaks quietly, sounding defeated. The issue of the gravesite will not rest for her. Clearly, this is something that she has been grappling with for some time. She sits across from me, looking down at the coffee cup in her hands, thinking deeply with a sorrowful look on her face. "I don't know.. It's um.. I guess it really doesn't matter where you're buried, but.. you want to be together, kind of. Like you said, you'd want to.. have your baby with you, you know...."*

*I'm at a loss as to how to help Deena through this, but I know that is not my place. "Yeah, you always feel that.. I mean, that.. after death it might not matter, but.. now it does, you know. You care about that now."*

*"That's right, yeah....." Deena trails off, having nothing more to say at the moment about this issue that is clearly not resolved for her yet. My heart aches for her, and I wish that there was something I could do, some words of comfort or encouragement to provide her with. But this is her battle, one that she will eventually work through for herself. I am confident that she will be able to work through it, because I sense an assertive, independent side to her despite her gentle nature and what seems to be her view of herself as dependent and emotionally fragile.*



I was never angry at God. I don't think I was bitter in that way. Maybe I asked, you know, in my mind sometimes, about it. But.. I have this feeling, like I have this.. peace in my mind that.. there must have been something that God knew that I didn't know. Because maybe he would have turned out to be just like his dad, or maybe he would have been sickly? Something I couldn't handle, you know. I don't think I blamed God, I.. I blamed myself more, I think. Thinking that it was something wrong with me. Especially when I had such a hard labour. Like I figured.. you know, why didn't I.. dilate like I should have and, um... what was wrong with me, why wasn't I normal like other women? Things I had no control over, but you think of those things... you know, why.. questions.

But my faith has been a comfort for me. I know that he's in heaven, and he's looked after good, you know. That... he's not suffering, I have that assurance. And ah..... you know I still think, what he would have been like, if he would have lived. At different times, or ages, how he would have been? He would have been walking, and talking, and.... I don't think you ever forget. And when you compare, I shouldn't compare I guess, but my niece and nephew are the same ages, or around the same, and you wonder, when they grow up. I don't think that goes away. Not for me anyway, maybe some people, I don't know, but I don't think so, because.... it was part of you...



*"I don't know what else I can tell you." Deena looks up at me from her coffee cup after a brief pause. Our discussion has wound down, and she looks emotionally drained from all that she has shared with me.*

*"Yeah, I think you've pretty much covered all of my questions."*

*"I.. don't know if I've been very good or not."*

*"Oh! You've been very, very helpful." I am reminded again of Deena's initial concern that she wouldn't have much to contribute. I am struck by her lack of confidence, and by her minimisation of herself. But she goes on to more confidently repeat two points that are important to her about her experience.*



*"But ah.. I don't think.. I don't think you ever forget. And you always wonder what they would have been like, and compare to other kids around the same age."*

*I'm aware of the need to wrap up our time together, but I suddenly have the impulse to share some ideas with Deena for how to carry on Shawn's memory for herself. "Um, I would just mention that, um... I don't know, everyone's different in how they.. want to deal with anniversary times and stuff like that, but, you know, I.. usually, like.. um, light a candle, or.. On the first anniversary, my parents came and my sister came, and we lit a candle and read a poem, and.. it was.. just to make it..." I trail off uncertainly, concerned that she'll think I'm assuming that my way of mourning is better than hers.*

*"Oh, yeah, that was nice! No, I've never done anything like that."*

*Encouraged by her response, I go ahead with the rest of my thoughts on the issue. "Yeah.. And, you know, some people, I think, find that hard. They'd, they'd rather not do that. But.. I think.. for me, it's comforting. And then my husband and I have a little birthday cake too.. I know some people think that's weird, but, you know it, it was nice to do."*

*"It's nice to remember, yeah. Well, if I would have done anything like that back when I was married to my first husband, he would have thought I was absolutely nuts, 'cause he said I was anyway," Deena laughs at this. It's good to see she has a sense of humour about it. "And I lived with him 9 years, but it was pretty hard, so...."*

*"mm, yeah.. no support there at all."*

*"No. Not a thing. I used to... I used to cry and cry, I know I did, because I didn't know what I was going to do. When you're all alone..." Deena pauses for a long moment, lost in thought as she looks down at her hands. She looks up with a faint smile and says, "But it's different now... It's been good."*

*"mm, that's good. You have a supportive husband now."*

*"Yeah, very, very. Like he said last night, when I couldn't get him on the phone and I finally got ahold of him, and he said, 'Well, you know, you spoil me so much' he said, 'that I can't do anything on my own.' He said, 'Well, I'm so used to you doing everything for me, I don't know how to do anything.'" We both laugh at this, and I feel relief that Deena has some goodness in her life as well as the sorrow. And I'm reminded of her nurturing spirit and her strength that has been hinted at in her story, but that I'm doubtful she's aware of.*

*"He depends on you for sure, then."*

*"Yeah, yeah. But I don't mind, 'cause he's so good to me."*

*After what she has gone through and has held inside her for all of these years, I am grateful to this man who is so good to her. As I drive away after saying our goodbyes, I am left*

*with the feeling that I, too, am lucky to have a supportive and loving husband, one who is able to grieve and support me in my grief. And I am inspired by Deena's ability to survive as a childless mother for the past 35 years, nurturing others and giving of herself without bitterness despite the enduring ache in her heart for her lost children.*

## 5. ANDREW

For a man  
You have to be the strong one  
You have to be supportive  
You have to be the stoic person  
You can't cry  
I didn't cry for a long time

I 'took it like a man'  
And the way I took it like a man  
Was I poured a bottle of booze down my throat

And then I got in touch  
With my cultural side  
And found out that it was okay  
For me to release the emotions  
I was able to cry  
I was able to release the sadness I had inside



It has been difficult for me to find the words to describe my response to Andrew and his story. He represents so many things: a teenage dad, transformed by the stillbirth of his daughter; an articulate, eloquent, and inspiring young man who has lived through so much and is wise beyond his years; an aboriginal man, proud of his cultural identity, with a depth of spirituality that many people never know. Yet, these descriptions cannot begin to adequately capture the power of his story and the strength of his character. Perhaps his words will accomplish what mine cannot.



I'm a writer, originally from X First Nations Reserve. I'm 20 years old, I'm full blood. When I was growing up I came from quite a large family, and it kind of seems... tradition in our family so to speak, or kind of a curse in our family to lose children at early ages. My mother lost two children in pregnancy, and my sister lost her daughter shortly before her due date. And one of my aunts has lost quite a number of children. Large families were very common in aboriginal families from that era, the 40s and 50s, so both my mom and granny lost children at early ages.

This aspect of my story started in the winter, close to 5 years ago. I'd lived away from my reserve for quite awhile and I was getting into trouble where I was living, so I thought I'd come home. But when I got home I was having trouble with school and I was 16 years old, so I

dropped out of school that year. I was starting grade 10 and I just dropped out. And I went into a downward spiral – I started drinking again and started messing around with drugs. And I met Chloe at a party that winter, and over the course of the evening we both got drunker and drunker and stupider and stupider, and we ended up going back to her place together that night. And we had an off-and-on-again relationship for quite some time. She didn't tell me she was pregnant until a few months later. When she came to me and told me that she was pregnant, I kind of made my decision right there that I was going to detox myself, clean up. Because when I was a boy my father committed suicide, so I never really had a... a parental figure, and before that he was a very abusive man, so it was not really something I knew how to be was a good father. But that's what I wanted to be. I decided that I wanted to be that for her, be there for her, be a good husband, be a good father, be a... be a good man. Something I never saw in life.

During my attempt to clean up, I went through a lot of withdrawals, alone. There'd be times where I'd be sitting there in a dark room, just thinking, or there'd be times where I'd have a slip and I'd have a... have a joint, drink a little. And then there'd be times I'd just go for walks, go for long walks, and I spent quite a bit of time walking to Chloe's house. I spent a lot of time walking and thinking about what I was going to do, what I was going to buy. I started... um... selling, to provide for... started dealing in drugs to provide... so I could buy stuff for Chloe and whatnot. And as it was coming along, as the months were going along, I was getting a little closer to her, a little closer to her, and I kind of had the feeling that we were going to be together. There were a lot of people in that situation, I know guys who have like 5 or 6 kids with a bunch of different women, and they're really not fathers to any of them. And that's one thing I wanted to do, I wanted to break that cycle and be there for her.

And then... the day before my baby died I was out partying; I had a slip so I was gone for a few days. I didn't come back for 3 days, and when I got back there was a message, Chloe had phoned me, and she said it was really important that I went and talked to her. And this was 7 months in, so she was already starting to show, and I went to see her and she was...crying really bad, she just, she was scaring the hell out of me, she was sitting there and I knew something was wrong because she was sitting there and she had a cigarette in her hand, and she had quit smoking throughout the time that we were expecting. And I asked her, "Well, what happened?" I knew something was wrong, and she said "I didn't feel it moving and then I woke up and there was blood on the blankets." And, I said "What?!" and she... she said "There was blood on the blankets." I said "Did you go see a doctor?" and she said "Yeah," and.. I asked her "What'd he say?", and she started... she broke down and she said, "It died." And, to this day I've never gotten a clear answer why, how the baby died. I still have no idea how it happened, all I

know is that she felt a lot of pain in the lower part of her belly, and she was bleeding internally. So I still... I'm not too certain. And I asked her "Well, what happened to it, what happened to it?" And she said, "They took it."

The doctors had given her an injection to induce labour, so, she – the baby – was born, stillborn like that. And it was a little girl. And I asked Chloe what happened to it, and all she said was "They took her, they took her." And I asked her "Where'd they take her?" And they said they took her downstairs to the.. the.. I guess the morgue. And I said, "Well what are they going to do with it?" She says, "I don't know." So I talked to Chloe's mother, and I said, "Well, what are they going to do?" and she said she took care of it. And they buried her in one of those common graves with a couple of other stillborn babies, and I'm not too sure where, I was never informed of that.

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*"Have you tried to look into it-?" I break out of my relative silence up to this point in the interview, unable to contain my sadness and concern for Andrew at this revelation. I remember how indescribably important it was for me to have my son's ashes with me after his death, and how excruciating it was waiting for the day I could pick up the urn from the funeral home. And I recall my horror the first time I read stories of how stillborn babies were frequently buried in common graves in past decades, not given the honour of a private gravesite that would assert their individuality, their identity as human beings. I silently remind myself that maybe it was different for Andrew; maybe this was not as important to him.*

*"I tried, but it's.." he sighs audibly, and I realize that this was a significant issue for him, as well. "I keep on hitting brick walls brick walls brick walls, because I'm.. even though I'm the biological father I don't have any say in it."*

*"Did they not have you listed on the Stillbirth Form or anything?"*

*"Nope. I wasn't listed as father, so.."*

*"Yeah, that makes it hard then.." It saddens me but does not surprise me that his rights as a father cannot be upheld without proof of his paternity.*

*"Yeah, so.."*

*"And do you have contact with her at all that she would look into it for you, or?"*

*"Chloe would maybe help me find out, but she, that's a part of her life that she's wanting to move on from, she's, she, um, after all this happened we started, we were together for a few months afterwards, and then we started arguing and fighting, and, then, we started, we both fell off the wagon, we both started going into severe alcoholism, and finally... enough was enough and we went separate ways. Um, she moved away and I stayed here. And she, she now has a*

*career, and she's... she's got her own life again. She's actually.. she now has two younger children.. or she now has two young children, she's with somebody, and she has completely moved on, we don't keep in contact anymore, the last contact I heard from her was when she informed me that ah, she was getting married or something, she was with somebody."*

*"mm, yeah, somebody else.. So what's it like for you not knowing, not being able to know exactly where your baby was, um- ?" I wonder if it has been haunting him, as I suspect such a scenario would have affected me. I recall the feeling of peace that I had the morning after I picked up my son's ashes from the funeral home. I need to internally shake my attention back to Andrew, away from my own painful memories.*

*"Um-m, it's kind of ah.... kind of confusing in some aspects, but.. I could feel her presence around me all the time. Like I, I've had the chance to travel a bit internationally, and whenever I go to places I can feel like somebody's with me, and it's a very.. it's a feminine, a feminine feeling, like a little-one, so I have the feeling she's always with me, so that comforts me. It'd be nice to know, but I think it'd also be.. it'd kind of spoil the feeling I get."*

*"yeah, yeah, like that's not her anymore at the cemetery.."*

*"yeah... so it's kind of, I'd like to know, but I wouldn't like to know, I'd like to let her rest in peace wherever she is, and know that she's with me in spirit."*

*I am relieved for Andrew, relieved that he is able to reframe his situation in this way. I hang on to this glimmer of hope as he continues to tell me about his journey of grief and healing after his daughter's death.*



I didn't have any regrets that I was unable to see and hold my daughter. At the time, I wouldn't... in our culture it's tradition that you show the body, respect it and whatnot. But at that time I didn't want anything to do with that aspect of it. At first Chloe went through a lot of denial, like, "My baby's not dead, my baby's not dead," until she cracked. That's what her mother told me, that at first she was going through, "No, it's not true, it's not true!" And I said that a few times, but I knew that it was true. I had the hindsight to know that this is true. And I saw my sister go through that, and I knew then that it had happened. So I kind of said, "Okay.... I'm going to have to deal with this, do I, do I want to see her, do I want to hold her?" And I thought, "What am I going to do, am I going to get angrier, am I going to flip out?" So I thought it'd be better not to. And then I found out it was too late to do it anyway. That was one thing I was really concerned about, that was my first concern, and that was the first thing I ever took care of in the situation was, "Okay, I don't want to, I don't want to, I don't want to see her, I don't want to carry her." And that's one thing I still stand by is, had I done that, I probably would have snapped. I don't regret

not having had that experience. Which I guess some people might find kind of selfish or cold hearted, but it's something that I knew right away I didn't want to do. Because... I've been around death for a long time, but it was different with my daughter, because I knew that if I had held her I probably would have put up a fight for them to take her away from me. I knew I'd probably end up doing something crazy like that, so I decided, "I don't want to, I don't want to." And... now a few years later I'm glad, I still stand by that decision.

My family's experience of losing babies kind of helped me in a way, because it kind of prepared me for what was going to happen. Particularly with my sister, when she lost her baby, it was her first child, so everybody, the whole family was rallying around her, and when it happened it was just a shock, because they had gone so far as they had the baby's room set up and they had the clothes. And that was probably the most painful thing we had to do was to clean out the bedroom, put all the stuff away. And in fact, it was a very detrimental thing to her marriage, because her husband has never really shown a lot of emotion to his kids since their first baby died, because he was... ready to be a father, and he was ready to take on responsibilities. He's not a man who shows a lot of emotions, he really hasn't been very emotional to his kids. And in fact they're getting divorce proceedings right now. It's, that's how... detrimental it was to them, that not only was there the pain of losing a child, but it really brought their marriage to an end.

Despite my family's familiarity with losing a baby, I didn't share a lot with anyone close to me after my daughter died. I really didn't talk to anyone about her death. And to top it all off, I've had a drug and alcohol problem for quite some time, and not being able to deal with it, not being able to express how I was feeling drove me... back to those... back to the bottle, back to the drugs I was into. The way I dealt with it was... I drank, I, I went into, I just went and got stupid, I... I was wandering for a long time, I'd go from party to party and whatnot, and I... it took me a long time to get my bearings again because I had saved up quite an amount of money to prepare for all the stuff like bottles and Pampers and whatnot, and I basically took it and I drank it up. So when I ran out of options like that, I found myself bumming change downtown so I could get a cup of coffee.

And... the one thing that helped me out throughout everything was my culture. I was never brought up in a cultural house. Both of my parents went to residential schools, so I was brought up in a very Catholic household, and I was never really in contact with my culture. But I went back to the Reserve, and I started talking with an elder and he told me about a place, a school that helped out aboriginal youth. So I went to the school and I talked to the principal, and I told him my background, and asked if he'd accept me. I told him that I was a former gang



member, I was a recovering alcoholic, a recovering drug addict, and that I had lost a child. And I said, "I would really like to get my life turned around, would you be able to help me?" And they said "Yeah." And they helped me a lot. The place I went to had a lot of talking circles, had a lot of sharing circles, healing circles, and in that time I got to vent, I got to share all my emotions and I also got to discover a love of writing. I got to write a lot, and that is where I expressed all my feelings. What I was feeling was put onto paper.

I didn't go into a lot of detail about my baby in the healing circles; this is the most detail I've ever gone into. But I'd say, "I've lost someone very close to me, and it was a younger person, and it's been difficult coping." And I told them there had been times where I wanted to... there were times where I'd be sitting there and I'd hold a bottle in one hand and a knife in the other, and thinking how easy it would be just to cut my throat or slit my wrists and end it all. But then I would figure that I'd be doing the same thing that my dad did to me, and I'd be denying any future children I'd have of having a father if I did that, I'd be denying future generations of knowing what it's like to... knowing my story. And I didn't want to become... I didn't want to go down the same road as my father did.

Those sharing circles and talking circles allowed me to get a lot out, and I've cried quite a bit during the circles. There'd be times where I'd talk for 15 minutes or I'd talk for 3 hours non-stop about it. And I'd tell what I was feeling then, what I was feeling now, how I'd predict I'd feel later on. I did a lot of sharing... I could share because of the fact that there were people there to listen to me, and the fact that the elders didn't criticize. That's one thing I was really scared of was being judged as though you're just another guy who knocked somebody up and, and...turned to the bottle again. And I didn't want people to judge me like that. That's one thing I was scared of was that I was going to get that stigma attached to me that I was a... I was just another drunk Indian that had a kid and didn't take care of it, that somehow people would think that it'd be my fault. Because of my past, and all the chemicals I put into my body.

That's one thing I thought of was, was it me? Was it a result of something I did, was it something I ingested, I don't know if it was anything like that... And, was it Chloe? For a few weeks afterwards I was kind of wondering, "Well, did she do something, did she have a smoke, did she have a drink?" For 3 days there was a lot of blaming, we were blaming each other for... We took care of that, we dealt with that aspect, but it really wasn't the same after that.

It's kind of like, for a man, you have to be the strong one, you have to be supportive, you have to be the stoic person, you can't cry. And, I didn't cry for a long time. I basically, I, I took it like a man, and the way I took it like a man was I poured a bottle of booze down my throat. And it wasn't until I got in touch with my cultural side and found out that it was okay for me to release

the emotions, and I was able to cry and I was able to release the sadness I had inside. And... I'm glad I had that opportunity, because I've seen guys who've gone through what I've gone through, like my sister's husband treated it that way, I've seen guys who just crack, and they go nuts. And I cracked and went nuts but not to the extremes I've seen some guys go to, and that's one thing I've really wanted to avoid.

Probably what led me to change was the fact that I saw so many guys who were doing what was expected of them. I mean what was expected in terms of the stereotypical reaction, like guys who would go drinking, drowning their sorrows. And, I could see myself going down that road, and as I was going I *knew* that I was heading down that road, and I knew I didn't want that for the rest of my life. So I kind of allowed myself to go through it for a little while, kind of get it out of my system, that way 50 years down the road I'm not going to snap out of the blue and go on a binge. That's one thing I wanted to do, I wanted to get that binge out of me before I... blacked out on somebody. I didn't want to end up being one of those guys sitting behind the cells, sitting in the city cells in the drunk-tank, wondering how they got there. And I was lucky in all the times that I was getting into trouble I never had an altercation with the cops, I don't have a police record and my finger prints aren't on file. Nothing. I was lucky and I knew that my luck was going to run out sooner or later. So I wanted to quit before it did.

It's been something I've wanted to do for a long time, it's always been a strong goal of mine to not follow the statistics, not to be another aboriginal youth behind bars, an aboriginal youth who's hooked on substances and going to be for the rest of their lives. That's something I've wanted to avoid. And, I figure... I must be, I don't know, either lucky or crazy or something, or even have a... I don't know, an abnormal sense of sanity, because there's been a lot of things that have happened in my life, and to be able to cope with them and try to keep everything level and try to keep everything normal and sane... it's been a... it's been quite the juggling act.

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*We pause briefly in our discussion, with Andrew taking a deep breath after all that he has shared, and me sorting through the thoughts and emotions I'm feeling at his powerful, compelling story. It dawns on me suddenly that this is the most open he has ever been in talking to anyone about his daughter. "So what's it like, then, having talked about her, you said this is the most you've talked about her?"*

*"I feel, mm...very... reminiscent, like, I'm thinking back on the days and all the kinds of stuff I was doing, and now I'm kind of, in my head I'm kind of thinking, 'okay, this happened, I did this.' What would I have done back then if I had the choice, would I have really, if I knew, knowing what I know now, would I have done what I did.."*

*“mmhm, you mean going and drinking after and stuff, or..?”*

*“Yeah, well, not only that, but, earning, like the way I was earning my money, and I could have tried, like, I didn’t even try I just kind of.. it was something I knew how to do so I did it. I, now, right now I’m just thinking back on a lot of, ah, things, the way I could have handled it, and particularly afterwards, how I could have dealt with it. I, I really wish that before all of this happened, before I went down that road, that I would have had the support systems that I had later on. But in retrospect I’m kind of glad I did go through it because, like I said, I don’t want it to come kick me in the arse two decades down the road.”*

*“Yeah...wow, that’s a pretty amazing story, I mean it sounds like even though you didn’t feel able to talk directly to anyone about your experience, you still found a support system through the healing circles.”*

*“Ya... it’s been something, like I give a lot of credit to my culture and a lot of people who helped me out of the situations I’ve been in, because, when I was in the Catholic faith – I’m no longer a Christian, I’m a First Nations traditionalist – ah, had I talked to Catholic people in my family and community, I would have been looked at as... it’s a major sin to have sex before you’re married, and even as a young person, you’re really... there’s really no support systems for young people in that kind of situation, particularly men. Like there’s women’s shelters that women can go through, but there’s no support system for men for dealing with that kind of thing, and society kind of thinks okay, well, you’re a guy, you’re supposed to.. you know.. act like.. take your lumps kind of thing. But... that’s one thing I’m really concerned about is the young people ’cause I, like I’ve got a cousin who’s 14 years old and she’s 8 months pregnant. And... I see a lot of our young people going down that road, having kids even younger than I was. I was considered a late starter in my family, in terms of the people that were doing that. Uh, so, I see these people, I see our young women getting pregnant younger and younger, and that’s ah, I’m just hoping that they don’t have to go through the kind of stuff I did.”*

*I’m struck by the maturity Andrew voices for a 20 year old, and I can only imagine what he’s gone through and survived – a young aboriginal man, faced with the suicide of his father, drugs, alcohol, teen pregnancy, and then the death of his daughter – and somehow, through some inner strength and resilience combined with the support of his culture, finding a way to reach his goal of beating the odds. I am somewhat in awe of him as he goes on to tell me about his career and the influence his daughter continues to have in his life.*

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*In my career now I work with an organization where we go into northern communities and we do presentations on STDs, drugs, sexual health, violence, and gangs. And that’s one thing I*

like to do is serve as a role model. I tell my story. I don't go into a great amount of detail because the people we're talking to are young. And that's where we try to talk first, is the younger people, so they know what is coming up, and they know the kind of pressures that are out there. That was one of the key factors – with me leading the life I led – because there was a lot of peer pressure out there. As a 16 year old guy, if you're not trying to... to snag every girl that you can, and get as drunk as you can, and party as much as you can, people look at you funny. That's one thing I had was a lot of peer pressure. And I go into the communities now and I talk about using birth control and preventative measures so that they know that they don't have to be a 14 year old girl who's getting pregnant, or a 16 or 17 year old guy who's going to be a dad. And I basically tell them, "Look, I can tell you guys don't do this, don't do this, but you're going to go do it anyways, so I'm telling you if you're going to do it, be smart about it, be safe about it, this is what could happen, this is what I've seen." That's one thing I try to talk to the younger people about is, "This is the road I've been down, and hopefully you can learn to make better decisions than I made." And had I had somebody when I was younger, telling me, "Don't do it, this is what could happen, are you really prepared for it?" I probably wouldn't have done the stuff I've done.

My desire to help others in this way came out of all of my experiences, but with my daughter's death, that's the one that's always in the top of my head, that's the one... like I wake up every morning and I look in the mirror and I have to deal with a lot of stuff when I look in that mirror. I have to deal with, "Okay I've done this, I've done this, I've done this." And the top thing, the first thing that comes into my mind is, "You know, your daughter could be 4 years old, or 5 years old right now, she should be starting school. And she's not going to. She's lying in a box somewhere." And that's something I've got to shake out of my head right away, because it's very painful to think of that, it's very self-damaging to have that thought. But it's inevitable.

When those thoughts come, I'm afraid of going down the same road that my sister's husband did. I'm afraid that if I do have children in the future, I'm not going to show emotion to them, the way he did, because of the fear that, "Okay, if I've loved one child and this child was taken away from me, why should I show emotion to another child if they're just going to be taken away from me?" And that's another fear I have is that I'm going to lose another child. That's always a fear that's in my head that with my fiancée, when we start to have our family, is this going to happen again? Is it something genetic, in my DNA, that's causing this? Or, is it, once again, the stuff I've done? Those are probably the biggest fears I have.

I had to grow up fast when I was younger, and that's not a situation I would want anyone else to be in. There's a lot of guys out there who wouldn't take that responsibility, and for myself I... basically had to grow up when I was a kid and I had to see my father in a box. That's when I

started growing up. And I thought, “Okay, I’m not a kid anymore,” so I kind of had to dummy up pretty damn fast or else I was going to get snowballed and I was going to be just a psychotic mess. So I had to really mature way before my time, and I’m regretting it now, because, the situation I’m in, I’m in a position where I’m a role model, and I really didn’t do the kind of stuff normal teenagers do. I never had that opportunity, I couldn’t be a normal teenager. I could have, but the situation that I was in, it prevented me from doing that.

But if I hadn’t had the experiences I’ve had, I might not be doing what I am today. In retrospect, in the long run it’s working out to be good, but at the time, during the times when all this was happening, it was very painful and it was driving me to the edge where I didn’t know what I was going to do, or how I was going to do it, or who I was taking with me. If I could go back and have the knowledge that I have now I’d still have my daughter and I’d still be able to do what I’ve been doing in terms of helping youth. But who knows, if my daughter had lived I probably wouldn’t be in the situation I am now.

That’s one thing I’ve been thinking about a lot is, what would have happened if she had lived? I don’t know if I’d still be on that road I was on. I may have been stronger because of the fact that I would’ve had to be mature and responsible; but I might have still been involved in the kind of stuff I was in. I don’t know if she would have grown up to see me sitting at a table with a bunch of bottles in front of me, or a pile of pot, or me and her mother arguing. Because as it went on we began to argue more, argue more, argue more – and particularly after it happened the arguments escalated to the point of shouting matches. So that’s one thing that I think about is, had she lived, what would she have seen?

Her death was one of the big factors in jolting me into changing. It was the final straw for me. I figured, “Okay, I’m done, I quit, no more of this, I’m going to have one last bender and if I survive it then I’m going to change.” That’s basically what I told myself. “If I survive what I’m going to do, then I’ll change.” And I survived. And hopefully I’ve changed; hopefully this isn’t just something that’s temporary. It’s been a few years now, it’s been quite some time since I’ve been in my new lifestyle. And I’ve had a lot of time to think, and I’m pretty sure I’m never going to go back to the way I’ve been. There’s always a chance – once an alcoholic you’re always an alcoholic kind of deal. If it happens, it happens, but at least I know that for a little while I was okay, for a little while I’d cleaned up.

And hopefully my little girl’s going to live on in terms of what I’m doing, and her spirit will continue to help others as she helped me. There’ve been times where I’ll be sitting there and I’ll just be down and depressed, and got the weight of the world on me, and I’ll feel that little presence. And then I’ll just perk up right away, and that’s when I return to the culture, I smudge

with sweet grass and whatnot. And I've gone on many pilgrimages to the States, to holy places in the States, and I've left bundles for her, in her honour. And before I do anything spiritual I pray to her first, and pray that she is with me when I'm doing anything. Because she's one of the pure spirits, she never had the chance to do anything rotten, to do anything negative. So she's a pure spirit, and I pray that she helps me when I do stuff like that.

I came to this kind of understanding of her when I was standing on a peak in Wyoming, and I looked around me and I saw eagles flying above me and I knew I wasn't alone on that peak. I stood on top Devil's Tower and I saw those eagles flying, and it was the third anniversary of what would have been her due date. I didn't realize it until I got up there, and then it kind of hit me. I was just like, "Whoa!" And I had to sit down and take a breather because my head was spinning. When I looked up and I saw those eagles, I knew that it was a good sign, and I could feel her with me there. It's kind of a coincidence that every year I attend these seminars in the States for at-risk youth, and they always fall on what would have been her due date. Every time the anniversary of her death comes around, I smudge, I always take it into consideration, I always like to take time out and I think about that.

I'm reminded of her when I see little girls, like when I see a father walking with a little girl on his shoulders, I think, I could be doing that. Or when I'm talking to friends and their little girl's talking, or the baby. And that's one thing hopefully in the future I'm going to have with my fiancée, is to be able to share that again. My fiancée knows about my daughter, and it felt good to be able to share that and my other experiences with her. I told her before we got into stuff, I said, "There's some things I've got to tell you about me before we do anything." And I explained to her all the stuff I've been into. And she knows that we both come from pasts. And for all I know, when I was getting into trouble, there had been times where I woke up in other people's bed and whatnot, I could have other kids for all I know, I have no idea, but this is the one I know about. And she understands that fact and she knows that that's a part of me, and she's totally supportive of it. And she knows that there are times where I'll be sitting there and I'll be looking just depressed, and she'll come, she'll talk to me and she'll ask me if I want to talk. It's good that I have her to be able to communicate with.

I've had a lot of support from people internationally, because I've told my story, not this part of my story, but I've told my story to people from around the world when I travel, and I'm a keynote speaker at a lot of seminars and whatnot. And that's one thing I've had is a lot of support, and people say, "If you need to talk, here's my mailing address, if you're ever here, come, we'll talk." And sometimes I'll go out to the Reserve, and particularly if I'm feeling really, really down, really, really upset, I'll go have a sweat, I'll go sit in the sweat lodge. With the



culture, that's one thing that has really helped me out, the constant support I have with the culture.

I feel one of my biggest successes is that I've avoided having to see a counsellor. There's been a lot of mental anguish but it's never been to the point that it has driven me insane. Because the only person who can drive a person insane is yourself. And I didn't want that to happen, so I thought, "Okay, I've got to deal with this in a way that's going to help me and not have a person constantly badgering me on a couch." So I dealt with it in my own way and having someone there to listen, having someone there who's not going to judge me. And I've found, I've worked a lot with some shrinks, psychiatrists and whatnot, and I've found that they treat their patients as just another case. Whereas the individuals I've shared with see me as a human being, they see me as someone with real emotional qualities and not just going by what a certain book they read in college says. So I'm glad I've had that kind of support.

I guess my cultural healing has been a form of therapy. It helped me a lot. I'm a very open minded person so I've looked into a lot of cultures, a lot of philosophies, Buddhism and whatnot, when I was still trying to figure out who I was. And I found, for the majority of them, there's quite a select few that allow a person to not feel guilt for anything. Instead of being ashamed of anything, you can actually be yourself. And the traditional First Nations culture is one where you can actually feel like yourself. Even though the drugs and alcohol, that aspect I had, is frowned upon by the culture, if you've gone through it a person's not going to say, "Oh, well you can't do this because in the past you did this..." They look at it as, "Okay, you've moved on. Where can you go now? And how can you help yourself?"



#### A Name to Rest in Peace

My daughter was never given a name at the time of her birth/death. She was just called "Baby Girl," and her mother's last name. But I named her myself a short time ago. I had a dream, and to our people dreams are powerful, and I swear I was given the name in a dream. It was a few years later, but that was the name I was given. In the dream I was given she was a little girl about two years old, and she came up to me and gave me a piece of paper and the name was written on there. It was Melissa Riel. So that was the name she had. That's the one I think of all the time now instead of just "my girl". That's the only way I know her by. I don't know her as anything else but the name that she gave me.

The dream happened when I was at a seminar in Australia. I was thinking about her, and I wondered, "Can she rest without a name?" And I was thinking about that when I was over there, and somebody had asked me my daughter's name, and I said, "She doesn't have one."



She was never born with one.” And then that night I had the dream. It all fit into place. And it has helped having a name to refer to her by. That’s what I call out if I’m ever having a rough time, I’ll just say, “Melissa, I kind of need your help.” Whenever I’m having a hard time, that’s what I think of is her name.

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Meanings, Longings, Self-Blame, and Transformations

*There's a curious freedom  
Rising up from the dark  
Some kind of strength I've never had*

*Though I'd trade it in a second  
To have you back  
I gotta try to make some good out of the bad* ~ Cindy Bullens (1999)

The one thing that really has helped me out, probably the most, is the fact that there is a purpose for this. I was told by an elder that there was a purpose for this happening, and this elder said that when individuals are born, they serve four purposes in life. And those four purposes are different for everybody; everybody has a different set of four purposes. And my daughter has served those four purposes, I'll never know what those purposes are, but she served those purposes. And when that's done, that's when you can return to the spirit world. I have a good feeling that the purposes she served me were: the fact that she showed that I didn't need those chemicals that I was taking; that I could continue with my schoolwork; that I was going to continue helping other people; and that her mother and I weren't going to have a very happy relationship together. I think those were the four purposes she served, those were the four lessons she came to teach us by the time she left.

And although the fact that she served those purposes helps me, it'd really mean a lot to me if she were here in physical body. One thing I've always wanted is daddy's little girl, to be able to buy stuff for her and be one of those fathers that you see on T.V., the real supportive ones. I would have loved to be there for her first words, for the first time she walked. Those are things that I really wanted to do, those were the things I pictured myself doing when Chloe first told me we were going to have a baby. Walking with her, teaching her first words, feeding her. And it was just like having, all at once, all these dreams and notions I had, ripped apart. And particularly to come back after doing what I was doing and have it happen.

I felt a lot of guilt from all of that. I was thinking, “Oh, I should have been here, I should have been here!” I felt like hell because I left Chloe hanging. And I told her, “I’ll be back,” and I just went out, I was just going out for a party, a buddy of mine had gotten out of jail so we went

on a little celebration and it was a long celebration, a few days' celebration, and then to come back and have that happen... I kept thinking, "I should have been here, and had I been here, maybe I could have taken her to the hospital quicker, or.. something... if she was starting to have pains I could have taken her in or told her, 'you know, you should go to the hospital, you should go get this checked out...'"

But I've come to some peace with all of those thoughts and feelings. I left it all when I went on one of my pilgrimages. I've gone on several pilgrimages to deal with certain aspects of the whole situation. I've dealt with the drugs and alcohol part now, and on each individual level I've dealt with specific aspects at different times. So those things I've had to deal with, I've given them back so they're no longer a part of me. Well, they'll always be a part of me, but they're no longer a part that's going to influence me into doing stuff like that anymore.

I would say I've definitely been changed and transformed by my experience. The person I was and the person I am are two different people. I still have some of the same old instincts or thoughts that I used to have, but I'm not the same person anymore. My priorities have changed quite a bit. There was a spark of the way I am now in my past when I found out that my daughter was going to be born. That's when the spark was first lit, the knowledge that I didn't want to be the way I was for the rest of my life and I was going to be there for this family I was making. And, in spite of having that family taken from me, that spark is going to continue with my new family; it's going to help when I do become a father again, if I become a father again. So the fact that that spark was lit then and it's coming into now is very comforting. It's always been with me. That's a comforting thought.

One of the ways I've changed is I find new ways to deal with stuff, I don't deal with things the old fashioned way I used to. I don't drown or ignore or bottle up problems now. Particularly with the relationship I'm in now, instead of letting things sit and stew and whatnot, we talk it out. As soon as something happens we talk about it right away. We ask each other how we're feeling. That's something I would never have done, I would have said, "Oh well, water off a duck's back," and just bottle it up and let it sit and eat away. That's something I would never do now. Even the *thought* seems kind of horrid to do that now.

I also have a better understanding of and outlook on life than what I had before. When it happened I thought it was the end of the world, but now I think, "Okay, I can move on, I've moved on, I can do this, I'm never going to forget that it happened, but I can look at this as either a positive or a negative thing, or I can look at it as a lesson I've been taught, and what am I going to do with this lesson?" And hopefully I'm doing with this lesson what is supposed to be done with it; hopefully I'm not going to let this go to waste. Because it was given to me for a

purpose, having this happen, it wasn't just fate or something, or just a cruel act of God that this had to happen for me. That's what I believe. It hurts, the fact that I had to go through it hurts, but I think, "Okay, there's a purpose behind this, and what that purpose is I have to find out." And if I don't find out then I've got to figure out, "Okay, what am I supposed to do with what I've been taught? How can I turn around and use it to benefit instead of being detrimental?" Because everything can be turned around and used for benefit.



*As Andrew finishes speaking, I find myself inspired and touched by his strength, courage, and wisdom. I search for some way to communicate this to him. All I can come up with is, "mm, that's great... Well you... I think you're wise beyond your years!" We both laugh at this, breaking the spell of Andrew's articulate storytelling and bringing us back to the present.*

*"Well when I was 16 I was 36, and when I'm 36 I'll probably be 16!"*

*"Regressing.. or catching up?" We laugh again, and I realize it's one of the first times during the interview that we've allowed ourselves some humour amidst the intensity of his story.*

*"Probably catching up. I did get to do a lot of the stupid stuff as a teenager, but a lot of it was way to the extreme, way more than I should have, and now, thinking back I often think, okay, all the stuff I used to do - what the hell was I thinking? There had been situations where I have no reason to be alive right now, like I did the stupid things like drinking and driving, and playing with guns and getting into fights and lipping off to the wrong people, and those are situations where I should probably... not be here."*

*"hm, yeah, really lucky, or there's a reason that-?" I recall Andrew's spirituality and his belief that his daughter's death had a purpose, and I find myself wanting to know more about his spiritual beliefs. As he has spoken I've felt a sort of reverence toward him, as though I'm in the presence of someone with a quality that goes beyond psychological strength. There is an aura of spirituality about him, and I find myself wondering whether it's his grounding in spirituality, his ability to make sense of his world through his traditional cultural spirituality, that has buoyed him throughout all that he's been through.*

*"Yeah, there's a reason, somebody... somebody has been watching over me. And particularly now – I have somebody very special watching over me. So I'm glad that that person's there because, it's like, for a long time I didn't have a piece of me, a piece of me felt missing – after she died, and even before that – I didn't have... there was... I never really had anybody I could look to. But now I have somebody, I know that there's somebody with me, and I don't feel as alone as I did. It was the kind of situation for a long time where I could be in a room*

*with a crowd of people and I'd still feel alone. And I don't feel that way anymore. I haven't felt that way for a long time, 'cause I know she's always with me."*

*"Well, that's a pretty special feeling..." I feel somewhat envious, wishing that I, too, could always sense my child's presence with me, rather than just the fleeting moments I've experienced from time to time. As we pause in our discussion, I feel a wave of exhaustion, which I suspect Andrew is also feeling. Although there is so much more I'd like to talk to him about, I realize it's time to wrap up the interview so that we can both leave and mull over what has been said and felt.*

*"So, how do you feel now that you've gone through the interview, any other thoughts...? Any questions for me, or whatever?"*

*"Well, I feel that I've gotten a lot off my chest... And I'm just glad that hopefully I'll be able to help somebody, and help with your research, and the fact that from this pain, from the pain of having lost a child, and the pain of having to go through all that I've gone through, the fact that there will be a positive aspect coming out of it in the long run. That's a very... that's a very healing thing, and hopefully through this other people will be able to be healed. And, like I said before, so other people don't have to go through what I went through. That's one thing I'm really hoping is that nobody will have to go through the kind of... the kind of pain and sorrow and anger that I went through..."*

*"If you could've had somebody like yourself, you know, back when this happened, someone who could've helped you in that way, how do you... what do you wish could have happened differently?"*

*"Well, if I.. if I had gone back and told myself these things, first of all I probably would have told myself to piss off and mind my own business, because that's the kind of guy I was... But... it would've been nice to know what's going to happen, so I could've prepared myself a little bit better. And of course you can't prepare yourself for anything in life, so... But it would've been nice to kind of know, okay, this is going to suck for a little while but it will get better. Ah, 'cause when it first happened it just seemed like... this is... the end of the world, it's always going to be like this, I'm always going to feel this bad, and it's going to hurt for the rest of my life. And, if I had had somebody tell me, 'No! It's not going to, the only way it's going to hurt for the rest of your life is if you let it, if it just sits there, then it's going to hurt.' But to know that it's not going to... if I had known that it wasn't going to make me... ah... a drunk, or it wasn't going to make me someone that's going to wallow in self pity and grief for the rest of my life. And, if I had known that, I probably would have handled things a lot differently than ah... than the way I did. But like I said, if I hadn't led the life I led, I wouldn't be around today, I wouldn't have had the*

*opportunity to do what I've done since. And plus, who knows what could happen down the road..."*

## 6. SHARON

*The phone rings as I'm cleaning up the kitchen after supper. My stomach does a small flip, knowing it could very well be another bereaved parent calling about the ad that I placed in the paper 3 days ago. I take a deep breath to compose myself.*

*"Hello?"*

*"Yes, I'm calling about the ad in the newspaper, about the study of long-term grief?"*

*"Yes, this is Myrna. You're interested in the study?"*

*"Well, I'd like to hear more about it.. I'm kind of hesitant about getting involved in something like this, and I'd like to hear how you are approaching the topic before I make a decision."*

*"Oh, definitely, I understand. Well..."*

*I go on to talk with this bereaved mother, Sharon, for about an hour and a half. As we talk, Sharon tells me large pieces of her story, some of the most significant elements, I think: her second baby, Tasha, lived for 18 hours, she had trisomy 13, and now, 17 ½ years later, Sharon believes her daughter was passively euthanized because of her condition. Besides these more general qualities, Sharon and I also have a very strong connection because my son also had trisomy 13. This coincidence strikes us both as significant, and Sharon notes that I am the first person she has talked to whose child had the same condition as her daughter. After our conversation I hang up the phone feeling somewhat shaky. I hadn't expected to meet someone whose experience hit so close to home. The implications of this new personal connection wash over me, and I feel both excitement and anxiety over what this could mean for me and for Sharon.*

*80*

Sharon, who was in her early 40s when I first met her, is the mother of 3 living children in addition to Tasha. Her career interests are in the realm of childbirth and breastfeeding, something that she was interested in before her daughter's death, but did not begin to pursue until recently. Her birth philosophy is a very important part of who she is, a part of her identity. Her emphasis on trust, dignity, honouring birth and all that goes with it, and women's rights in the realm of childbirth have emerged from her history of feeling disempowered as a woman in birth. Birth for her is a spiritual thing, and even though her subsequent pregnancy after her loss

resulted in a healthy baby girl, she felt, “There’s more to the birth experience than a live, healthy baby.”

We met 3 times for tape-recorded interviews, twice to explore Sharon’s story and once to explore mine. She offered to interview me about my story, given her interest in our mutual experience of having babies with trisomy 13. We also met on a few occasions for more informal “mother-to-mother” sharing of our common experiences. Together, we have considered the personal meanings that having children with birth defects had for each of us. We compared notes, we shared pictures and mementos, and we formed a bond that will likely continue beyond the life of this project. Sharon is a very articulate, intelligent, and compassionate woman who has a lot to teach people through her experiences. Her story radiates with the strength and compassion that she embodies.



### The Birth and Death Story

I’ll start with my son’s birth, because I’d just like to say a few things about my birth experiences and philosophy in general. My *first* birth, of my son Grayson, was very traumatic. I had thought I was well read in the area of birth, and I would just squat down and birth my baby out. But it turned out that he was in a posterior position, which made birth difficult. He was born with me up in stirrups, and with forceps, and they did an episiotomy on me that went past my anus. It was *incredibly* hard to heal from that. I mean, I couldn’t *walk*. I was *really* in rough shape. I couldn’t sit for a month! I couldn’t sit. So you know, the healing, both physically and it was also very emotionally traumatising, it was difficult

But anyway, it’s just something that happens, life goes on. Like I said, you’ve got to find your way through that, and keep going. So after that experience, I thought, “Okay, that’s not happening again. I’m not having that happen again.” I knew adamantly that I didn’t want any drugs – any pain relief, or analgesics, or anaesthetics of any sort – because that would put me more at risk of having a forceps delivery again, and I was *not* going to be having those things put in me again. I was sort of convinced that Tasha’s birth would kind of redeem me. I felt bad that I couldn’t push my first baby out, with me being so young and fit and everything I felt I should have easily been able to do it. So afterwards I felt quite inadequate.

I did a *lot* of reading and really prepared spiritually and emotionally and everything for Tasha’s birth. I was feeling *really* good about it, and I spent some time seeking out a good physician. I had a female physician with Grayson, and I mean, it *really* hurts to be hurt by another female. I thought, “No, I’m not going for another female again.” So I chose a male doctor, an elderly doctor, a kind man, and I spent a lot of time talking to him about what I wanted



for the birth, and he *basically* knew that I wanted to give birth as naturally as possible, and under my own power.

So I was very prepared when I went into labour. I felt really good, you know, this is going to be a good birth, and expected that it would sort of redeem me. But I didn't have a good nurse at all. Not a nice nurse at all. Just as bitchy as they come. But I thought, "It's okay. She's not going to get in my way." I had a very nice resident though, a very nice fellow, very kind. And they pretty much left us alone, except the nurse would come in and I'd tell her I don't want this procedure, or I don't want that medication, and she would be huffy, and you could just *tell* that she was into being in control. And again, this was 17, 18 years ago, when things were different. So I just kind of laboured away, and I think it was around 8 o'clock that my waters released. And that was when the nurse was the *most* bitchy. She said, "Okay, you have to lie down *right now!*" And I was saying, "Not now." I mean, you can't speak very much at that time, I just said, "Not now." But I was very aware of her attitude, I didn't like it at all.

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*Sharon: The urge to push overwhelms me. I feel like I'm in another world, focused only on the sensations in my body and on pushing my baby out. I stop pushing as each contraction eases up, and in the periphery of my attention I know the nurse is there, and my doctor and some others, but they're not in the birth world with me. I push again and I can tell that the baby's going to come with this one! I reach down to touch the head as it emerges from my body, and I feel wet, curly hair plastered over my baby's head. "Oh baby!" I feel a wave of absolute ecstasy and profound love for this tiny human being. Any minute now my baby will be on my tummy. Suddenly, a voice breaks into my consciousness. "Sharon, take your hands away." Oh God, oh God. There's something wrong. Oh, maybe it's the sterile field, I got my hands in the sterile field, I better take my hands out of there. No. That's not it. **Something's wrong.** I dimly hear my doctor's next words as my world comes crashing down from the heights of ecstasy to absolute devastation. "Baby's got a cleft lip. She's having some difficulty... We're going to have to take her."*

§

They took her across the room and began resuscitating her. She wasn't breathing. She was very blue. I just remember the rush, and then all the attention going over there, and watching him resuscitate her, they were bagging her. I remember saying, "Come on baby, cry. Come on baby, cry." Because there was silence in the room. You know, not hearing any kind of a cry. I won't forget, too, the doctor picking her up and turning her over, and.. slapping her, just slapping her up her back, and quite roughly, and me thinking, "That's quite rough, but.. she

needs to be stimulated, she needs to get breathing..” Ah, but she started to breathe, and started crying a bit, and that was good, I felt good about that. And... at *that* point, I thought it was a cleft lip, and nothing else. I didn’t *think* there was anything more. I *know* now that my doctor knew that it’s likely the baby had trisomy 13. Now that I’ve studied in birth, there’s *no* way that anybody goes in to be a birth practitioner and doesn’t study some of the major trisomies, and what to look for. So I know he knew, but he didn’t tell me. He was a very nice man, and a very humble man, and to this day I hold *nothing* against him... for *anything*. Even for not telling me. I feel no ill will towards him at all. I can only imagine what a difficult situation it was for him, although I think he *could have* handled it better. But I don’t feel any kind of ill will towards him.

So then, okay, I saw the cleft lip... and I thought, “Okay... so she’s got a cleft lip, so we’re in for more surgery. We’ve done it with Grayson when he was an infant, we can do it again, this is going to be *way* less complicated.” When Grayson had his surgery there was a little boy that was in for surgery on his cleft lip. I’ll never forget that little boy. He was in one of those baby swings. I think he was about 5 months old. And he was just *smiling*, just *so* happy to be in that swing. But, you know, with a cleft lip, the smile is just.. all I can describe it is, his face was just so *open*, you know. But his parents were *so* joyful that he was happy, and they said, “Isn’t he beautiful?” And I said, “Yeah, he’s, he’s *very* beautiful.” And that was the first thing that I remembered, when I saw Tasha is.. you know, she’s beautiful, *of course* she’s beautiful. However, that is still a tough thing for me, because.. you know, everybody wants a beautiful baby. That’s what we’re expecting when we give birth to our babies, is.. is a, you know, a beautiful, whole, complete, fully formed baby. And, when there are things wrong, it’s very hard to take... And I mean, you know that too.

80

*Myrna: My husband and I sit in the darkened ultrasound room, waiting for the radiologist to tell us the results of our 18 week ultrasound. I’m still grinning from the excitement of seeing the blurred image of our baby kicking and squirming on the screen moments ago. As I make a comment to my husband about the videotape they’ve taken for us, the doctor knocks and opens the door. He tells us that the dates are as expected, and that everything looks good... except... they think the baby has a cleft lip. It’s hard to tell the severity at this stage, but it’s likely just a unilateral cleft. He tells us he’ll send the results to my obstetrician, and we’ll plan another ultrasound around the 28<sup>th</sup> week to get a better view. I look over at my husband, and can tell he’s not sure what to make of this either. We ask a few questions, and then walk together to the parking lot. He has to hurry back to work for a meeting, but says before he leaves, “The doctor said it can be easily repaired.. it’ll be okay.” I’m still slightly shocked as I drive back to the*

university, with a lump in my throat and thoughts racing through my mind. Damn it! How did this have to happen? Our poor little baby has to go through surgery? What about breastfeeding? Will we take pictures? I give my head a shake, thinking, **of course** we'll take pictures. There's nothing to be ashamed of. I feel my mother bear instincts kick in as I think about our baby being judged for his appearance. I pull into the parking lot, and as I turn off the car, I let the tears come while telling myself it's going to be fine, we can handle this, and it could be **so** much worse...

...My parents arrive in the delivery room as the nurse finishes cleaning up Jacob's body and wrapping him in a big blue towel. They've warned us about the other birth defects, the ones we didn't know about, but my mind hasn't been able to absorb this new information yet. The nurse with the sad, angelic eyes comes to the right side of the birthing bed and hands me my baby for the first time. His cleft lip is worse than I had expected from our prenatal visit with the plastic surgeon. I'm kind of taken aback at first, as I'm sure the others are as well. I feel like a bad mother for thinking that his nose and lip look horrible. But then I look past his lip and nose to his other features. He has his dad's eyes, his cheekbones, his forehead. I try to ignore his lip as I touch his face, mumbling, "poor little guy.. poor baby." We'll never get the chance to know how we would have dealt with his cleft lip, his birth defects, his disabilities. All the preparation for the cleft lip before his birth, and now it doesn't matter. It doesn't matter. He's gone.



I remember my doctor coming in and saying, "In your birth plan, I see it reads here, if the baby needs to be transported, that you wish not to be separated." And he said, "But we can't do this, there isn't room. There's only room for the baby, and you'll have to come separately, in a separate ambulance." So I said, "Okay, well my husband will go.. and follow." So they went. They just.. took her. And then my.. my least favourite nurse came back to kind of wash me up and stuff. And then she turned to be *all* compassionate and loving. And I couldn't handle it. I just basically closed my eyes and let her do it, but I couldn't stand her presence, and that *false* compassion. I couldn't stand it. I'm not a... a bitchy kind of a woman. Like I'm, I'm... I'm a nice woman, and I try to be really nice to people. Even if somebody has hurt me, I'm *still* nice to them. But I wish I wouldn't have been as nice to that woman. When she was washing me and being *all* nice and gentle and loving, I just thought, "Fuck you." I thought to myself, exactly these words, I can remember, "Is this what it takes to get some compassion? I've got a child who's going to go through some rough times, and this is what it takes." And obviously *she* knew that this was a dying child. They all knew. Yes, definitely there were signs there, and I wish I would have been told right then and there. Because I wouldn't have waited for them to transfer me by ambulance

later, I would have said, “I’m *going*, with my husband. Wash me up, give me the cloth, I’ll wash myself up.”

§

*Sharon: The nurse wheels me into a ward room full of women. “This is the gynaecology ward. Here’s your bed.” She helps me out of the wheelchair and gets me settled. Man, this is a busy ward. I don’t really belong here. Oh well, all that matters is that my baby is okay. I look toward the hall, and my husband appears in the doorway. “Hi! So where’s the baby, how’s she doing?” He pauses a moment and looks around the room. “I have to tell you something really difficult.” The look on his face suddenly registers, and my heart begins to pound. “She’s not going to live.” Shock grips my body, making it hard to breath, hard to think, hard to hear. “What do you mean, she’s not going to live?! What do you mean?! She only has a cleft lip, and the doctor only talked about some minor surgery!” I’m sobbing uncontrollably as I slip into another world again, this time a world of nightmares and horror. I hear Timothy explaining that they think she’s got a chromosomal condition. Dear God, this can’t be happening. I manage to sob, “Well take me to her right now! Take me up to her right away!”*

*They wheel me through a maze of hallways, with my husband following beside me. We don’t speak, can’t speak. We enter the neonatal ward and move past tiny bassinets, and then pull up alongside one of them. Oh, baby, baby. An i.v. tube is hooked up to her tiny body, and an oxygen apparatus is around her head and nose. She is breathing fairly quickly, but seems stable. I notice the skin around her eyes looks really red. “Did you put silver nitrate in her eyes?” The nurse looks up from her chart and says, “Yeah, I did that in the ambulance on the way over.” Damn it! It’s not what I wanted! I told them in my birth plan that I didn’t want silver nitrate in my baby’s eyes! I bite my lip as anger merges with shock and devastation.*

§

Some of our siblings came up. My brother was good in facing me and supporting me, but would not come in and see Tasha. Although, I *know* him, and his kind of problems with sickness and death, and his difficulty with facing them. He never wanted to face things like that, he never wanted to go to any funerals, or if he did go, he never wanted to see the body if it was an open casket. My sister came in though. I won’t forget her standing beside Tasha, and stroking her head and saying, “You’re very beautiful.” That meant a lot to me to this day.

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*Sharon pauses briefly to take a sip of tea. I’m conscious of having said very little up to this point in the interview. Sharon’s story flows out of her as though she has told it in this depth a million times before, rather than to only one or two other people before tonight. I am particularly*

struck by her memory for details, even 17 ½ years later. The details appear important to her, an integral part of her only memories of her daughter, and therefore unspeakably precious, however painful.

The topic of her sister's response in a recent telephone conversation is pressing on her mind now. "I was really pissed off about a month ago when we phoned, and we were talking, and.. she forgot Tasha's name, and.. I mean, that, that kind of~ You know, and then, and then.. we were talking a little bit about Tasha, or that experience, and I started to cry a bit. And she said, "Oh, I'm sorry." As if she shouldn't.. you know, be.. talking to me about it. She just sort of doesn't have a clue about.. you know, dealing with grief. And that's.. you know, one of these things I'm sure that you're studying, that people, as soon as they see grief coming, they back off."

"mmhm, mmhm, don't want to make you cry, yeah," I murmur, quite familiar with this experience with my own family and friends.

"Yeah, don't want to make you cry, don't want to hurt your feelings, and, you know, uncomfortable with that. Um, and that's why I think, you know, finding a community of people that.. know that actually you do kind of like to cry about this sometimes. Ah.. and it's okay, it's not hurting you, it's not--, it's, it's.. part of this."

"mmm, yeah, you need to cry sometimes." Although I have much more I'd like to say and to ask Sharon, I'm conscious of how much time has passed and how much of the story we still haven't covered. With each participant I've interviewed I have questions and feel a connection, but with Sharon I am constantly aware of our common experience of having children with trisomy 13. It is difficult not to cut in at times, to offer my agreement and bits of my own experience, and to ask questions that might steer us off the path that her story must take.

8

Sharon: I look up at the clock on the wall as I stand beside Tasha's bassinet. She's 6 ½ hours old. She's stable. Maybe she'll live for a few weeks yet. I don't want to leave her side, but with all this standing.. man, am I exhausted. I look over at my husband. "Timothy, I think I need to lie down for awhile. I'm scared to leave Tasha though.. what do you think?"

"You should rest. We'll just make sure the nurses know where we are. Remember when Grayson was in the hospital? The nurses took good care of him when we had to be away. Speaking of Grayson, maybe I should go check on him while you rest. Poor little guy has never been away from us this long."

"Yeah, you're right. I'll just talk to the nurses." I get the attention of the nurse who has been monitoring Tasha. "You know, I, I've got to go to go lie down. I just, I can't.. I can't stand

here anymore. I'm feeling kind of weak, and, and she's stable. You'll stay with her." She says, "Yeah, I'll stay with her." "Stay with her, and call us if there's any change. If there's any change, call us immediately." I look at Tasha once more before turning to leave with Timothy. Oh, baby. I swallow back a lump in my throat. Timothy and I go back to my room. I lie down, and Timothy sits on the chair by the bed. "Will you hold me?" I ask, feeling the need to connect with the only other person who really knows what I'm going through. Timothy comes up on the bed and we hold onto each other, and despite the strain on our marriage in the past months, we're brought back together by the impending death of our baby girl.

Shortly before 5 a.m. Timothy gets up to leave. He tells me he'll go check on Tasha again, and then head over to see how Grayson's doing. I roll over as he walks out the door. I'll just close my eyes for a minute...

What time is it!? I jolt awake, and my eyes search wildly around the room. 7 a.m.! How could you fall asleep, your child is sick!! Jeez, what happened? How could you fall asleep like that?! I look around the room and realize that I was awakened by the sound of food trays being delivered. I need to check on Tasha! I can't leave without checking with the nurses though. Where are they?? I don't know how to get to neonatal on my own. But I guess nobody has called me, Tasha must be okay. I might as well eat. It's been a long time since I ate anything, and I'm famished.

I gulp back some breakfast, and still no nurses have come in. I get up to look for someone, and a nurse walks in the door at that moment. She rushes to another woman's bedside before I can get her attention. Oh, they're too busy.. these other women look like they're in a lot of pain. I feel bad bothering the nurses. But I've got to get going! I pull on a bathrobe and slip toward the door. I feel like I'm sneaking off, but I've got to get to Tasha! After some wandering I find the neonatal unit. I push the door open and head to the spot where I left Tasha a few hours ago. I notice that I don't recognize the nurse writing in her chart across the room. Shift change must have happened already. I reach the bassinet where Tasha was and my heart sinks to an all-new depth. **It's empty.** Oh, dear Jesus. I look around frantically, and rush over to the nurse. "Where's my baby? Is she dead?" She looks confused, scared. She stammers out, "I, I'm not sure. I'll check with someone else." She rushes out of the room and returns in a moment with another nurse who says to me, "Come down here." She leads me to the very back corner of the nursery. Tasha is lying naked in an uncovered isolette. She's lying on her side and her skin is a terrifying shade of blue. I feel agonizing grief well up from the depths of my soul. "She's dead, isn't she?" The nurse says quietly, "No, not quite."



At that time it never entered in my mind that they were passively euthanizing her. *None* of this, until a year ago, came to my mind, that that was a possibility. It was just like... I don't know! I just... in the moment, just went to my baby. Lying naked, no blanket or anything. Nothing. Nothing. Just in the corner. And I think I remember saying, "Why isn't she covered?!" And they said something about, "Well sometimes when they're cold it stimulates the breathing." And ah... you know, like I.. I kind of remember that comment, but again, that's an unclear comment. Who said it, when it was said... um, maybe I'm wrong, but I, I'm quite sure it was said. But thinking to that now... what, *what* is that?! You know. Like if you know this baby is going to die, then why not wrap this baby up? And make her nice and warm and cozy, and let her die warm! Why let her die cold?! Ah.. and ah.. I, I just don't get it. But these are some of the things I'd like to ask them! "Did, did you really do that?" I would like to find these nurses and say, "Did you really do that?" I'm sure there would be denial though. There's no mistaking that she was alone in the corner, but I can't say whether it was for a long time. I mean it's something that nags at me, to find the answer out. Because I feel.. *that* I *do* carry ill will about. But sometimes I say to myself, "But don't carry ill will... if that wasn't the case. If.. if they *were* being very compassionate and caring to her, if they *were* standing alongside of her, and stroking her." Maybe they just had to go and help another baby for a moment. I don't know the answer to that. I mean, maybe some day, on the other side [after death], people will *have* to be honest at that point, and maybe I can find this information out *for sure*.

So then they wrapped her up, and plunked her in my arms. And ah... I remember just.. weeping, sobbing. And putting my head down in her, and just weeping like that, and them walking on each side of me and taking me to this cozy room. And um.. me sitting there, and the nurse, I said, to the nurse, "Phone my husband and tell him to come *right away*." And ah.. and she went out, and I was alone with Tasha. And ah.. you know, just kind of looking at her, and weeping and crying, and.. and then her taking... just, all of a sudden she took a sharp, gasping intake of breath. A *very* sharp, long gasp. And she did that 3 times. It was a *long*, sustained gasping for air. And.. I mean, I was *shocked*. I just... I just went, "Oh, baby!" And I almost felt a sense of... *punishment* at that time. I mean it was, it *was* punishing, to me, to witness that. Um... you know, I, I can't describe it as anything else. It was..... *the worst* thing that I have ever witnessed in my life. Um.. like there was no *joy* in that she's breathing again. It's like, "Oh my God! Oh my God!!" I was so fearful, in fact I felt almost like I wanted to put her down! I was scared! She scared me, actually, she was *very* powerful! She was *very* powerful at that moment. And I, I mean, sometimes I think, and, I don't know if I can *justify* it, or give it a meaning or anything, but sometimes I feel like it was God breathing into her. There was a lot of power in that



room, and I, I honestly felt like getting down on my knees and covering my head, at that point, and putting her down. I was very scared. I was *very* scared..... But I didn't do any of that, but I.. I was just *so* scared *of her*, at that point. Scared of her power, of that life force flooding back into her.

Um.. so she had started breathing, and pinking up again, stabilising, so to speak. And the nurses came in, and I said, "She just started to breathe again." And I think they were shocked. And um... so then Timothy came back. I remember the neonatologist coming in at that time, and I, I said to him, "She's hasn't opened her eyes, she's never opened her eyes to look at me." And he said, "It's likely she doesn't have any eyes. Or if she does, they're very small." That *really* hurt. That *really* hurt me. Um.. like not, not that I'm angry with Tasha or anything, it's just like, "Oh-h, God." You know, "Why that?" You know, "Why no eyes?" It's kind of like getting bad news and then more bad news, and more, and it's like, "Oh God, can there be more? Is there anything possible that could be *worse* than this?" Everything else to me was.. was.. *nothing* compared to that particular defect. That particular defect is still really bothersome to me.

Timothy was there, and she was struggling to breathe. It happened once where it was a little bit of a gasp and Timothy got quite startled. But Timothy never saw what I saw. He never witnessed that. And I'm not sure if I've really even told him about it, in that kind of depth. I just felt like he doesn't need to know that. I mean, it was *very* painful for him. {voice breaking} He would have traded.. you know, in a second, ah.. spots with her, and given her health. His health. {crying quietly} .....Even though we're not communicating well right now, I have a lot of respect for his pain. And for his love and dedication to her. He's very dedicated to her.....

We were in that room when my parents came, and my in-laws came. Nobody could really say much, they just had a hard time saying anything. They didn't make any comments about her cleft lip. I'm not sure if they really noticed, although.. the nurses did bring oxygen back in again, and put some tape there, so I think her lip was covered. My mom did make some sort of mention about, "Oh, what's that by her lip?" And, I said, "Oh, that's the oxygen Mom." Ah.. my dad, my sweet dad, who passed away 10 years ago, he was a real sweetheart, and I, I love him and I miss him dearly. It's hard to explain his personality, he was not a very talkative man, but he knew there were duties that one had to do in tough situations, and he would always be the one to stand up to do those duties. And he said, "I'll sit with you." And he sat down. My mom left, and we said, "No, Dad, I think you should go too." But he felt a duty to *sit* with us, to be with us, not to leave us alone. {voice trembling} And ah.. ah.. I kind of wanted him to go, 'cause I knew she was going to die. And, I.. I guess I felt a sense of.. I don't think I want my dad to be here. 'Cause it

will be too hard on him. So I asked him to leave, but I let him know how much we appreciated that he was there.

At one point I had to go to the bathroom really bad. And I was afraid that she would die when I left to go to the bathroom, but I still had to go. So I got up and I went to the bathroom quickly. And when I was coming back, I walked past the coffee room where the nurses were. And I heard, out of the coffee room, I didn't hear who said it, but I heard, "Isn't that baby in the cozy room dead yet?"... I mean I, I took that comment, and I just.... I don't know how to explain it... it registered in me, and it went somewhere *so* deep within me that I could *not* deal with that comment at that point in time. I was just *so* focused on going to the bathroom, pee fast, and get back to Tasha.



That comment came back to me just a few years ago when I went into these memories. At the same time though... all of these things, I've always *known* about them. And they've *bothered* me over the years. But *really*, this whole thing that happened with Tasha, I shelved it. I just took it and I shelved it. I couldn't deal with it. I didn't want to *think* about it, I mean, of course I wanted to... think, and remember my child, but I just couldn't... deal.. and I don't think I even understood what happened, until many years later when I *believe* what happened became clear to me, that this *was* probably euthanasia that was happening. I guess, too, I have a sense of... if I ever brought that up, people would say, "Yeah, but your baby was going to die anyway. So why would you want to prolong the struggle and suffering of your child?" Almost as if *I'm* not justified to be *angry* that that happened. And so I've been quiet about it. Because I'm *afraid* of having that comment made to me, "She was going to die anyway." Because I know that would hurt me, very much. Because what it does, is it dishonours her, and devalues her life. And I can't handle that! I have had *many* comments, from family members and others, like, "Well, it's better that she died. It's better that she wasn't a burden. She would have been a burden. She would have likely been very disabled. It's better that she died, if she would have had to live like that." And I think, "Why?! Why?!" I found a quote in a book by Donnali Fifield, a mother who had twin babies die, one of whom would have had cerebral palsy if he'd survived. She had some contact with *severely* handicapped children after her sons died, and she came up with this quote to describe one of the children, it's *so* incredible. I just *wept* when I read that. She said something like, "Within the confines of his disability he had as much *ability* to have love and joy and sadness as we do. Within the confines of his disability. And who are we to judge what confines are to be valued..." It was *so* incredible. That's the *first* book I've ever read that *spoke* exactly how I'm feeling.

At one point after Tasha's death we had to go back to the hospital for genetic counselling, which was traumatic enough on its own. I just remember bawling the whole time. I wasn't feeling good about what they were saying, either, because they were saying things like, "We recommend an amniocentesis next time, and you would have the option to abort if the baby had the same thing." So *basically*, they're saying to me, "That child should have been an abortion." I was just talking to a friend today about a lot of medical practice being based on *fear*. And based on economics. When I think of what happened to Tasha, I think, that was driven by economics! It's very expensive to keep a baby in neonatal. And if they're not going to *live* very long, they don't want to spend that money. But what I'd like to say, and what I'm hoping that you will be able to relate through your paper, is that if that's the case, *tell* parents that. I would have *gladly* taken my child home. And I would have *gladly* had my child die in my arms in the *car* on the way home, rather than cold and alone in a hospital ward.

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Tasha died maybe about 2 hours after that. In our arms. When she died, there was just the two of us together. Her breathing just got shallower and shallower, and then she stopped. My husband was actually holding her, and I let him hold her even though I wanted to hold her, because I thought, "I've held her in my womb all this time." And he held her and he said, "I love her so much." {crying softly} I just didn't feel like I wanted to withhold that from him. I wanted to give him a chance to hold her too.

We held her for awhile. Ah.. cried. A lot. Um.. undressed her, looked at her.... I did feel a sense, when she died... that *something* came in the room and took her. Something spiritual came in the room and took her out. And at that time, I *did* become very spiritual. Not very spiritual, very religious. From a Christian point of view. And felt that that was Jesus that came and took her. And that gave me a lot of comfort.. for quite some time. I'm not... I, I would *love* to have that feeling again. But somehow, it's left me.

A neonatologist resident came in then and said, "You can take as much time as you want to be with her. And call us and let us know~" She was *very* kind, and *very* compassionate. And a nurse came in. I don't know who that nurse was, but *she* was wonderful. We asked what they were going to do with her body. And they said that.. they would call the funeral home, and so on and so on. Did we want an autopsy? Absolutely not, we didn't want anything more done to her body. And it just came to a point, I think it was maybe about an hour, an hour-and-a-half... where it was very apparent to me that she wasn't there anymore. And there was nothing that I could do. And if I could do it differently, I would have taken her home and prepared her at home. But I guess there was sort of an assumption that.. you don't do that. So we handed her over, you

know, and um.. {crying softly} that was the hardest thing to do... is when you hand your child's body over to somebody else. At the same time, I felt... "She's gone." But that was very hard to do.

Afterwards I was just so upset. I mean, upset about losing baby, but there was something much deeper that I was very upset about. But I couldn't.. I mean I just couldn't place what that was. But there was a sense of, "I don't want to be here, I don't want to be with these people, I don't want help from these people. I want to go home." I insisted on going home soon after, because they were trying to get me to stay, and saying "We'd like you to stay overnight, we'd like you to stay under observation and make sure you're okay." They were being very compassionate, and I mean, there were times of great compassion through the whole experience, and times of.. not. Real inconsistency of compassion in dealing with a very tough life experience...

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*Sharon lets her sentence trail off, looking exhausted. She pauses for a moment, and then says, "Um.... Yeah, and I don't--, I don't know what else, I think I'm kind of like, drained. I think that's it."*

*"yeah, yeah, it's kind of--, yeah" I stumble for words, feeling exhausted but worried Sharon has stopped so abruptly because she has not felt heard or connected to me during the interview. "yeah, can only spend so much time--"*

*"That's all I can do. Tonight."*

*"Yeah, yeah." Her addition of the word 'tonight' gives me some hope that she does want to meet with me again to tell more of her story. I turn off the tape recorder. Sharon gathers her things while we discuss the possibility of a future meeting to continue her story.*

*"I'm feeling sort of like this has been a very one-way discussion." Sharon says before she gets up to leave. I'm not sure how to take this, but assume she means that she had hoped to hear more of my story tonight. I point out that I wanted this first meeting to be about her and her story, and that we will certainly share more of our common experiences in a future meeting. I thank Sharon as we embrace one another at the door. As she turns and leaves the dimly-lit interview room, the fatigue and sorrow I have felt from hearing her story wash over me, and I can think of nothing but going home to cry and sleep.*

*While I'm preparing for bed at home, I notice myself feeling irritated in addition to mentally and emotionally exhausted. I write in my research journal the following morning, trying to process my confused emotions in response to my interview with Sharon.*

*"I don't know why I'm feeling this strange irritation," I write. "I like Sharon, she seems very well-balanced and compassionate and.. well, likeable. Maybe I felt criticized by her comment that the interview was one-sided. But she clearly meant it in an apologetic way, in terms of being sorry for not having a chance to hear my story... Maybe I'm reacting to how she talked about birth defect issues in a way that I haven't been able to voice yet, or in a way that I have denied I felt. She felt like others didn't value her daughter's life, seeing her as a mutant child who didn't deserve life, let alone compassionate treatment as she died. She also talked about being disturbed by her daughter's birth defects, particularly that her daughter likely did not have eyes. I think I have dealt with these issues in a way that Sharon hasn't. I know they still cause me pain, but it is not the pain of shame. Or is it? I guess that's what's bugging me the most. I keep thinking that maybe Sharon hasn't gotten past the birth defects because she is still ashamed. And if she's ashamed, does that mean I should be too???? I put out Jacob's picture at the prayer service because of my experience with people with disabilities. I thought long and hard and passionately about such issues long before Jacob came into my life. I refused to hide the pictures, because doing so would indicate shame, in my mind. In this society that generally doesn't value people with multiple disabilities, I want to scream at people: 'He was my baby. He was my son. He had a cleft lip and some other disfiguring birth defects. He probably would have been mentally retarded. And I would have loved him just as much as you love your children, and with NO shame. He would have, **did** have more to offer the world than do many perfectly (superficially) beautiful & intelligent people. And I am going to make you understand that if it takes the rest of my life.'"*

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## The Grief Story

*Sharon and I sit in an interview room four months later. Since our first meeting we have met two additional times and exchanged several e-mail messages. Sharon has shown a keen interest in my personal experience and thoughts on having a child with birth defects, and my grief reactions more generally. As she pauses mid-sentence to answer an expected cell phone call, it strikes me that I have really come to care about and appreciate Sharon – her insightful and compassionate nature, her interest in me and my son, and her desire to help others. I've never felt like she has wanted or needed to lean on me in a therapeutic relationship type way. If anything, she has voiced her willingness to be there **for me** if **I** need someone to talk to. I can't help smiling a bit as I think about what a switch this is from the formal, impersonal researcher-participant relationship that my early training emphasized. Sharon apologizes after she finishes*

on the phone, and then continues with her recollection of her family's intense grief the first few days after Tasha's death.

"I remember too, when I first saw Grayson when we got home from the hospital, you know, he was just a little 2 year old guy," her voice breaks again, and tears well up in her eyes, "and he came in and he said, 'Mom, did you bring a baby home for me?' I still remember that..." Sharon sobs, and I swallow back the lump in my throat as she reaches for more tissue. "So... just a little bit of an indication of what it does in the long term... I still think about these things, and can still be very saddened by them... And um..." She trails off, crying softly again.

"yeah-h-h...and it always comes back like.. comes back.. like fresh grief all over again." I am very familiar with the intensity of grief that still resurfaces now, nearly 3 years since Jacob died.

"Sometimes.. not always, but.. I mean, I'm not sure what it is that's triggering it this time to be... fairly difficult. Because I think I've talked to you other times where it hasn't." Sharon's voice is stronger now, as she seems almost apologetic at her display of emotion. "But um... so I think that's ah, that's part of it is.. over the long term... that you can recall things about this, and at times it'll be very difficult to recall them, and you'll have a good cry about it, and then other times you'll recall them without any tears or without any emotion. And I can't really put my finger on it.. probably hormones sometimes, like I find my times of the month, I am, I mean I just know it, I am more teary the week before my period is coming."

I am struck by Sharon placing a biological explanation on this seemingly normal aspect of long-term grief. Despite her irritation with society's tendency to push bereaved parents to "get over it," she is unconsciously affected by the same attitudes in blaming her natural long-term grief reaction on PMS. "yeah, yeah... seems quite unpredictable though in some ways too doesn't it?" I try to normalize her reaction, unwilling to blame my own similar grief episodes on my hormones. "I mean I find that I'll be having a great day, and just standing and washing dishes and suddenly just.. break down, like just out of the-, I mean my thoughts are going, but I'll be thinking just normal thoughts, and then suddenly there's.. some thought about Jacob, or, you know, something about Jacob comes up, and just.. waterworks, you know... such an odd thing, but.."

"yeah, yeah.. I think that's the thing too that.. what makes it difficult for people who've lost babies is.. that a lot of people don't understand that. And definitely the thoughts in the long term aren't.. kind of accepted as okay to do that. It's like, 'Come on, you know, it's been 18 years... let it go already.' And.. so.. you often find yourself... not sharing that with people, or suppressing it. But over the long term you definitely do want to continue to reflect on it, and talk



*about it. But your life becomes busy.. with other things. You know, life has gone on, and you've recovered to an extent from that very intense grief where you're just like.. numbed."*

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At first I wanted to be alone, and we sat and we talked.. my husband and me. It did bring us closer at first, because we had been having some challenges in our marriage. But then this big thing happens, and of course you've got to be together. I mean whenever people are having problems in a relationship, walls go up. And then the walls go down, and everything is set aside, and forgotten about.

I saw a movie recently where basically, this woman was doing a pretty natural reaction of grieving. She was *numbed* and unable to get back into life, and the husband was going back to work, and he was still strongly grieving, but he was sort of getting back at things. But she bitchier than hell, this woman, and bitchy to him when he would try and sort of get her out of grief. And my friend who I went to the movie with was really mad, she said, "She was so bitchy!" And I said, "You know what? That was me." I said, "I saw *her* in *me*, totally." Totally, I said "I *totally* understand why she was like that. *Completely*." And I said, "You know, I had my mother tell me to stop crying after 3 days, and my husband telling me at 6 or so weeks that it's time to move on, that's enough grieving, it's time to get on with life." And my friend, who's never experienced a loss of anybody very close to her, she just couldn't *get it*. And that to me exemplified how general society feels about loss. It's like, "Come on! It happened, get over it already! What's going on?!" It was hard to watch that movie. I was *really* bawling throughout. It was *really* hard to watch, because like I said, I saw myself in that woman.

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When Tasha was born my marriage was in a challenging time. We were fighting and arguing, and I felt he wasn't helping me enough, and being good enough to me when I was pregnant. I think pregnant women *need* to be treated very well, they need some extra care and nurturing. And I made a comment to him, and I didn't realise when I made that comment how *deep* that comment was going to go, and what it was going to do. I'm sorry I made it, but I said to him right in the delivery room, I said, "You were too hard on me during the pregnancy." This was after Tasha was born and was over in the corner and stabilised. And I made that comment to him, and he took that comment very deeply. I don't blame him for taking it deeply. But what I basically meant when I said it was, "That was a hard pregnancy!" I didn't know that the baby wasn't well, but it *was* hard. I think when you're carrying a child that's got a lot of problems, there's a lot of energy being taken from the mother. And so that's kind of more what I meant



was, "See, look, I was carrying a child who's not well, and you didn't have any sympathy or any empathy."

So *that's* why I made the comment. What *he* took that comment to mean was, "It was your fault. You caused it. It was your fault." I'm married to a guy that... trying to get him to tell his feelings is like... you need 5000 wild horses to drag it out of him. And so he internalized that comment, and held onto that for *at least* 10 years, before he finally said something to me. Although we became very close right after Tasha's death, our marriage deteriorated some months after. And it wasn't until about 10 years later that we got talking, and he *finally* came out and said, "You blamed me for Tasha, didn't you?" And I said, "I didn't blame you *one bit*." I said, "I blamed *myself*, all these years. I have blamed *myself*... And you thought that I blamed you. Why wouldn't you *say* that?!" You know, it's such a *damned* thing when you cannot *communicate*. Why I can go and speak to somebody who I don't even know well, like you, and I can communicate fine, or to a good friend of mine, but to my husband I can't communicate. We still have some *real* communication problems in our relationship.

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Years afterwards  
I can't say I felt *grief*...  
about losing her  
I became very *accepting* of the fact that...  
She's not going to be part of our life.  
I was *very* much in denial sometimes  
That it was a big thing.  
That it was a big thing,  
That it should affect my life.

I mean I was struggling to get back to who I was  
To *what* I was *before*  
The blow was big for me  
Because I had two,  
*Two* kids that had genetic problems  
That part is almost worse than her death  
The fact that she had..  
those problems  
It still bothers me  
I didn't produce a healthy child.  
In my own.. selfish.. ego.. way...  
that has really bothered me.

I didn't produce a healthy child  
And I thought,  
"What the hell is the matter with you?"  
Just kind of feeling like a real failure  
I felt so *down* about my body

the ability of my body to...  
have healthy children  
I blamed *myself*  
I was punishing *myself*  
What's the point.  
What's the point.  
Why, why..  
Why try and be healthy  
Why try and eat carefully  
Why...  
It's not going to work anyway.

I was a really fit healthy slim young woman  
I was an athlete  
A very disciplined athlete  
I was very health conscious  
And that just.. totally fell apart.  
Totally fell apart.  
I've been struggling for 18 years,  
And I haven't..  
I haven't been able to get that discipline back.

It's still a struggle for me.  
I mean anytime I take a piece of food  
that's not very good for me  
that I know is going to make me fat  
that thought comes back to me,  
"Oh, I don't care.  
I don't care.  
I don't care anymore."  
And so I have to fight against that.  
And I'm losing that fight.

I became somebody who I didn't want to be  
I had to get used to being this..  
new person  
Someone I never wanted to be  
I didn't really like myself  
very much at all  
I spent a lot of years in self hate



A couple of years after she died, I'd often go to sleep on a couch downstairs. I said I shelved it, but then there were times you're thinking about it. It'd be during those times where there was quiet in the house, it was later at night, and I'd watch these rock videos. And I'd watch like the most *bizarre* ones. I'd flip to the channel to find the most *weird* ones. And at that time, I mean that was the 1980s, there were some pretty.. *dark* kinds of bands and things. They were very.. ah, satanic almost. And weird. And I'd sit there and I'd watch those, thinking maybe I could

figure out why this all happened by looking at very satanic things, evil things? Maybe some answers would come about why that all happened. At *that* time, I would say I was *very* depressed then. *Very* depressed. Depressed about the loss... but *mostly* depressed about not having any *friends*, about being this new person, gaining weight, not feeling motivated to go and exercise. It's interesting when I look at family pictures from that period, and I'm always smiling and happy, and I think, *oh boy*, there was so much below that, and behind that smile. I was a very disempowered woman. *Very* disempowered woman. In some ways, I think I wanted to kind of *punish* myself? And ah.. not having anybody to talk to about it. I mean, I think I really needed counselling. *Really* needed counselling.

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*Sharon:* I'm gazing at a floral painting in my doctor's office, mentally sorting through what I need to discuss with her. I should just keep this simple, talk to her about my weight gain... But thoughts of my problems with Timothy and feeling down about myself keep intruding. Go away! I can't discuss that with anyone! But I need someone to talk to.

My thoughts are interrupted by a knock at the door, and my doctor enters the small examining room. "Hi Sharon. What can I do for you today?" My heart beats a bit faster. Should I talk to her? Can I trust her? No, I won't say anything. "Well.." I begin with the mundane health concerns, but as we talk my heart continues to pound. "I'm not too happy about all the weight that I've gained," That's all I'm going to say, I tell myself. Keep this about your health, nothing more. "I guess I'm concerned about how it's affecting my health, my cholesterol levels."

"Well, oftentimes when people gain weight it's a sign of something deeper going on." She looks at me with compassionate concern, waiting for me to respond. Oh thank God! She understands. She has opened the door, I can talk to her. I feel my guard dropping, and my eyes start to fill with tears as the words start pouring out. I tell her about my marriage problems, things about our relationship I never intended to divulge to anyone. She listens and then opens up the chart abruptly to make some notes. "Well, your marriage is in trouble, you need to go and get help, you need to see a counsellor, they know how to deal with this kind of stuff. Here's their card. Is there anything else?" She closes the chart, apparently finished with me.

**Wham.** The abruptness of her words and the closing chart feel like a door slamming shut in my face. Shame and confusion overtake me, and I mumble my thanks as she leaves the room. I stumble down to my car and somehow make it home and get the children fed and off to bed, with the haze of darkening, troubled thoughts spinning in my head. "My marriage is in trouble? Why did I say anything?! Stupid, stupid!" I walk to the liquor cabinet and grab a full 26 of whiskey. Maybe some aspirin too? No.. not yet. I need to talk to somebody. Who can I trust? Will

*anyone listen? I take another gulp of whiskey and cringe as it burns down my throat. I'm feeling numbed and calmer now, and I think suddenly of Marg, the only person who has given me some compassion since Tasha died. Tasha. Her name sends me into another round of tears. I scuffle through a desk drawer, looking for a pen and paper and Marg's address. I begin writing, knocking back another shot of whiskey every few minutes and pouring out my thoughts on paper. I finish the letter to Marg, and then start one to my doctor. My thoughts get hazier as the bottle gets emptier, but I keep writing.*

*I wake up on the couch in the darkened basement. My head pounds as I look around, trying to figure out what time it is. Light gleams through a small window in the next room. Morning. Dear God, I think I'm going to die. I rush to the bathroom and spend the next several minutes there. I wake up later with my face pressed against the cold bathroom floor. Must have fainted. I realize suddenly that I need to check on the kids. 'If Samantha was still breastfeeding,' I tell myself, 'you wouldn't have done this.' She and her brother are all that keep me going. The tears well up in my eyes as I call my mom after checking on the kids, who are still sleeping. "Mom, you've got to take care of Samantha today, I'm really sick." When she arrives I'm conscious of reeking of alcohol. She doesn't say anything about it. Not a word. I go up to my bedroom, feeling like I might faint again. 'You almost killed yourself last night,' I think to myself. As horrible as I'm feeling, I still realize that's not what I want to do.*



Yes, I was having communication problems in my marriage. The doctor was right about that. But I felt she kind of shut the door in my face, and I threw out some pretty heavy things. And boy, you've got to be careful when you open the door for people, don't slam it in their face. But Timothy found the letter, and he wouldn't talk to me after that. He would *not* talk to me. Only if he *had* to talk to me. And it came out a few years after that, that he told me about finding the letter to my doctor. And he was so angry with me that I told somebody else. He's so super private about our life, and I mean, he *wouldn't* talk to me. It was only *much later*, when I said, "What's going on here? Why won't you talk to me?" And he finally said, "I found that letter."

So with this quasi-attempt of suicide, I mean at that point, I thought, "If I die from this, then I die from it." I didn't care. And I think too.. I don't know if that attempt was... about the *grief*.. or the loss.. it was more.. *because* of the loss, this is who I had become, and I didn't like who I'd become. I was *totally* unhappy. The only happiness I had was with my children. I mean, my children were my bright spot. They were what sustained me, what gave me purpose. They're involved in this and that, you've got to take them here and there, you've got to make meals for them, you've got to entertain them. They were my focus that kept me going. But my marriage

was, I felt, *shot*. I wanted it to end. And it might have been better if it would have ended then. But then I wouldn't have had my youngest daughter, who is another one of my joys. My children are my joys.

During those years when I was so depressed we had neighbours whose daughter had severe disabilities from a chromosomal problem. It was kind of hard to watch. I think I kind of tried to disassociate, and *not* think, okay, that could have been *me*. But at the *same* time, I thought, that could have been me, if Tasha had lived. I'd kind of watch this mother, who was *incredible*. She was just *such* an incredibly strong woman, and *positive* in the face of real difficulties. I mean, I think I couldn't face it, because I thought I could never be like that. I could have never been like her... I was just going through real *weak* periods, feeling like a very *weak* person.

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*Sharon is quiet for a moment, lost in thought with her eyes fixed on a painting on the wall. The mention of imagining life if Tasha had lived sends Sharon's thoughts in a new direction. "Something that's kind of hard for me... very hard for me to admit, and I've probably only told a person or two.. but while Tasha was.. in our arms.. I mean I was just wanting her to die. And I feel very badly about that," she says, her voice breaking slightly.*

*"mmmmm...but not wanting to see her suffering, yeah." Sharon has mentioned this to me once before, and I can only imagine the agony of watching your child suffer. I think suddenly of the moment which, in retrospect, I identified as Jacob's final movements as he died in my womb, and the feeling in the pit of my stomach tells me I have a better emotional understanding of Sharon's agony than I first realized.*

*"But at the same time, watching her breathing the way she was trying to breathe, and oxygenate herself, and struggle.. and, I mean I know she had pain, she had to be in pain. There's nothing more excruciating for a mother than to see her child in pain and suffering. And.. I mean, maybe that was selfish of me.. because of.. the difficulty I had watching that. But also, I think part of it was for her. And, I mean once you've been given all of this news that.. your child is not going to live, your child is going to have this problem, your child is going to have that problem, there's this, there's that. Ah, and I think I told you before when they said.. she likely doesn't even have any eyes.. I mean I just... when that doctor told me that, I was like.. "oh-h God.. it's just too much, that is too much"*

*"yeah.. as if you didn't have enough already.."*

*"yeah, but too much for her. Too much.. for her to be able to live with and cope with.. And.. um.. and I mean.. in a way, selfishly, I don't know if I'd be able to cope with this, I don't*

know! I've got a 2 year old, how are we going to do this? Initially, when she was born and we saw the cleft lip and palate, I was like, 'Okay, well.. we're going to have to go through surgery again, and we've done it with one child..' Ah.. but the thought of multiple, multiple operations, and things and.. I mean as well, they did say, likely her cognitive ability.. I mean I can't remember, 18 years ago, whether they said she'll be mentally retarded. I don't think they did, because.. I remember that really would have bothered me. And I remember not wanting to hear it from anybody, from family or anybody.. saying, 'Well she would have been mentally retarded.' I just thought.. don't anybody dare say that. Um.. and nobody ever has, except for my mother-in-law in the last couple of years said to me one time, 'I was watching a TV program with all these children who were mentally retarded. If Tasha would have had to have lived like that, it's better that she died.' And even though I wanted her to die.. because.. I could just see that life would be so difficult for her... I don't appreciate those kinds of comments. It's kind of like.. I know that, don't rub it in, I don't need it rubbed in, I know it already, it's enough that I know it, there's enough pain knowing that, without somebody else.. you know, telling me that and rubbing it in your face and in your nose, and.."

Something about what Sharon has just said stirs up a mixture of unpleasant, uncomfortable feelings for me, reminiscent of how I felt after our first meeting. Even though I know how passionately she feels that her daughter should have been honoured and that her life was of value, I am left with the nagging feeling that, if Tasha had lived, Sharon would have had (or still has?) some shame to deal with about Tasha's multiple disabilities. In response to this highly inflammatory issue for me, I find myself wanting to remind Sharon of something she has said herself – that despite the painful challenges that they and their families face, people with multiple disabilities (like Tasha.. and my son) can play an incredibly valuable role in our society, if we open our hearts to learning from them. But how do I tell her this without sounding self-righteous? "Right, right.." I begin, searching for words. "Well and sometimes you can have both feelings, like.. you can feel that.. it would have been awful and whatnot, but you can also, like we talked about before, her life was of value anyway, you know, so.. you can have a mixture of feelings on your own, and for someone to say that, and sum it all up in, 'Well her life wasn't of value', that doesn't cover it at all, it's an insult."

"yeah, yeah.. and at the same time, I had this sense of.. I mean it's just crazy, the feelings that you have, because you have these feelings of, 'No, I don't want her to go through that, I don't want her life to be like that.' and then you have the feelings of, 'Oh, no, but maybe I could have, maybe we could have done it,' and maybe it would have made a better person of me. And, again, who am I to judge her life, I mean it's her.. struggle. And if she wants to go



*through this struggle and live.. then she should be honoured for that. But, nevertheless, watching her trying to breath.. I mean, she was gasping for breath, you know, breathing like that for hours.”*

*“yeah.. just wanting that to end, yeah,” I say, humbled once again by the complexity of this issue for Sharon, given the fact that she had to watch her daughter suffer before she died. When she speaks of knowing that it’s for the best that Tasha died, I know that a big part of it is because of not wanting more of the unfathomable pain of watching her child suffer physically and emotionally, rather than shame over mental retardation and other disabilities per se.*

*“And.. I mean I, I can’t explain how.. hurt.. how, how.. I mean you’re just totally helpless. Nothing you can do. Watching that struggle was... very hard..... And.. I think too... at some points, you’re thinking of the future, but at some points you’re thinking of what’s going on right there and then. But I think it was fairly clear to us that.. life would be fairly difficult for her. But that was.. absolutely excruciating, watching her suffer. I mean, I think about that sometimes, about... seeing one of my kids hurt. And I, I just think.. if something happened to any one of these kids.. that’s it, I’d be.. done. Finished. I would not be able to go through that kind of thing again. Never, ever. Um.. but, you know, sometimes you do have to go through things. I mean.. we.. in fact, we have dealt with more death in the family, and I know I will have to go through more things.”*



When I think back to the birth of my third child, after Tasha, it took me four years to even *think* about getting pregnant again. And I was *really* scared, *really* really scared. And normally the birth process was an important thing for me, wanting to have a good birth, and a *powerful* birth. Yet... I kind of went, “Just forget about that, just get the end result. A healthy baby.” And I was very focussed on an end result, rather than the experience. So during the pregnancy, with my anxiety about it, that’s what I was focussed on, the end result. But you know, after having a birth that was.. well, not highly intervened, but intervened enough that it disempowered me again, I came out of it going, “No no, there’s more to birth than a healthy baby at the end.” And I would like someday to help women who have lost babies, because I *know*, when you’ve lost one, you really do focus on, “Just give me a healthy baby at the end.” But with my fourth birth, where the *experience* was powerful, it was *very* powerful. It really helped me a lot. Not to say that there are other experiences in the world that can’t help soothe you, or make you feel better, or whatever. But birth was an important thing to me in my life. And I think women who’ve lost babies tend to, for the next birth experience, just say, “Do *whatever*, but give me a healthy baby at the end.” And I was of the same sort of feeling, and I’d like to kind of compassionately tell



those women, “You know what, if you have a *good* experience in birth, and you’re supported emotionally, it will really *help* you.” I try really hard to avoid the word ‘heal’, because I don’t think you ever *heal* from this. But it does, there is, there’s *soothing*, there’s a better sense about what happened in your life, a better perspective on it, coming to peace, and if you’ve been in a depression, sort of helping to pull you out of that.

I think what *happens* in subsequent births is the opposite. You get marked, you know, that you’re “at risk” or whatever, because you’ve lost one previous, you’re considered more at risk. I mean, I’ll never forget, with Samantha’s birth, our daughter *after* Tasha, the intern coming in, and going through this checklist, and saying, “Okay, so you’re first child had~” And ah, so here I am in labour, and the guy is going, “Oh! What an interesting past you have here. You had one son with this, and then you had a daughter with this who died, and~” Oh, I thought, “You asshole!” I mean, I couldn’t believe it! I guess I can’t believe it *now*. Back then, I was a lot younger, I *was* a very disempowered woman. So when I say “you asshole,” I’m saying it now, from the woman that I’ve become now. But at the time, I assumed this is what you have to do, this is what you have to put up with. It’s a *vulnerable* time for any woman during labour and birth, and women who have *lost* babies are even *more* vulnerable. *Ultra* vulnerable. I’d like to empower younger women to know that they *don’t* have to accept *everything* that’s said to them, everything that they’re told to do in those situations.



Over the years, thoughts of Tasha and her birth defects were not at the forefront in my mind, but just kind of more in the background, because I had two more children after her. And I also got very involved in my career. And so my mind was just very busy with other things, I was just *so* busy in life. Like I said, it’s almost as if I took everything about Tasha and kind of shelved her. Put it up on a shelf. And *really* didn’t want to look at it or examine it. I mean I feel *really* bad to admit this, but there were some years where her day would come and I wasn’t even thinking about it. I was *so* busy with kids or whatever, that I went, “Oh my God!” Timothy would say, “Make sure you go and take flowers.” But other times, I’d have to say there were times she became..... almost forgotten. Not *forgotten*, never forgotten, but I didn’t *think* about her. And now there are still some days that go by that I don’t think about her, but generally... *some* little thought will come in, almost daily. But it may be just a fleeting thought.

Another part of pushing everything about Tasha to the background for so many years was... well pretty much, I think because there’s a sense of *shame* associated with having a baby with birth defects. I mean, when Grayson had his problem, my husband was acting as if it’s a *shameful* thing for these two young healthy people. Not only was I very into health and fitness

and everything, so was my husband. We both felt we were going to have this brood of healthy, vibrant children. And so that was such a *shock* to us when Grayson had his problem, and then Tasha had her problem, and there was a sense of.. where he thought I blamed him for it. But when Grayson had his problems, my husband said, "Don't tell anybody." And until he healed from the surgery, I mean, I couldn't take him out. I mean, I wasn't afraid, I would have taken him out! It didn't bother me! My friend's daughter had a cleft lip! And they didn't *hide* her! They didn't hide her cleft lip, they took her out! But my husband said, "And don't even tell my brothers and my sisters." He was *very* controlling, when we were younger. He's no longer that way, but he *was* very controlling. I mean he had his way, and that's what he wanted, and he would just *really* go after me, you know, *arguing* and *yelling* at me if I crossed what he wanted. And I was a young woman, I was only in my early 20s and I just wasn't a strong, assertive woman. He was older than me, and a much stronger force or whatever, I don't know how to describe it. When Tasha also had birth defects, he said, "*Don't tell anybody anything* about her. No details." Even our families don't know that it was T13, they don't know. We didn't tell our family it was T13, we didn't. I think we said her heart had a bad defect in it, and things like that. But I didn't detail everything. I felt intimidated. And also feeling a sense of shame, thinking, 'I don't know if I want to share that with people.' And so I *didn't*.

80

Sharon: *It's 15 years since Tasha died. I sit at my new computer and click on the internet connection icon. It's my first day on the internet. I start up the search engine as my friend taught me, with every intention of beginning a search for the course I'm taking. But what I type instead is 'trisomy 13'. My thoughts have continually gone to this topic since I got the computer. This is my chance. I can do it anonymously, no one has to know. Timothy doesn't have to know that I'm delving into this. I look through the list of internet sites that come up, and select one. I find myself staring at pictures of children with chromosomal problems.*

*After much reading and tears, I spot a site dedicated to pregnancy and infant loss called "Honored Babies". **Whoa.** I feel like I've had the wind knocked out of me. 'My baby wasn't honoured,' is the thought that screams out at me, a thought that I realize has probably been buried in the back of my mind for years, but never fully came to consciousness until now. I look through the site's home page, and select a story written by the owner, Paula. A few sentences into her story I begin bawling. The tears flow down my face as the gut-wrenching sobs force their way out of me. My baby wasn't honoured.*

*Later I e-mail Paula in order to be placed on the discussion group list. There are 14 other women on the list. I read their stories and comments, and notice one woman's statements about*

wanting to kill herself. I think, "Hey, I can help these women. I've been through it too, and it might help them to know I'm okay now, this many years later." I type a message for the group. "You're going to be okay, you can make it. You're going to be okay, and yes these feelings will come, but you will be strong. Here I am, 15 years later. Let me be here as a testament to you, that you will go through difficult times, but you can make it." Thoughts about Tasha not being honoured keep popping into my head. No. I'm not going to say anything about that, about how she died, about the T13. They don't need to know that.

82

After taking part in the group discussion for awhile, I decided to strike up a private correspondence with one of the women, Karen. And because of the kind of person she was, and her own experiences, I felt like maybe I could tell her more details about Tasha. I didn't tell her everything at first, because I *still* didn't know her that well, and with e-mail, I felt like, "Who are you, I don't really know you." I really didn't trust her at first, I was *grilling* her. I was like, "Why do you want to know me? Why would you want to keep in e-mail contact?" But at one point I wrote to her and said, "When I came across the link to Paula's site, the name immediately intrigued me. You know, Karen, I never felt my baby was honoured." And.. she wrote back and she said, "Well, you know, usually the maternity ward is such a great place, and everybody's so happy because babies are being born here, and the nurseries are great places, I can't imagine why.." And, *oh*, I just started writing back things like, "No, they *weren't* good, and they *weren't* nice." And then I explained some things. At one point she called me, and I explained it *fully* on the phone to her. And *she wept* on the other side of the line. She was just.. bawling. And she was saying, "How could they *do* that to a young baby? How could they not even *cover her up*?" And she's like, *bawling* when she's saying this. And that *totally*.. got me. I was *totally*.. pulled into Karen at that point. Because it was the first person that *I* felt had really cried for my child. And.. and who cared about that.. suffering that she went through.

So when I talked to Karen about it, it all started to come out. And during this past 3 years since I got on the internet, I've gone through a sense of *needing* to tell this story to people. *More* people. But also needing to make sure that it was very *safe* to tell them, that they weren't going to make stupid comments. After telling Karen, I thought, "I *need* to meet this woman." And of course, she wanted to meet me too, it was a totally mutual kind of thing. I didn't want it to be just this remote electronic connection, I wanted to see her mementos of her daughter and *share* that and her life with her. Plus I wanted to see this woman who's crying for my baby, where I didn't have that over that whole period of time. I mean, I know that Timothy cried for her, but just having a friend. *To me*, what has sustained me in my life is friends. I *never* did feel, though, until

recently, that I had a friend that could be a good confidante for me. Until recently. I'd say Karen is probably my best confidant. I feel like I can tell her anything.

So Karen and I met, and she shared memories of her daughter, and I shared the pictures of Tasha, for the first time. Which I had never shared with anybody. Sharing with Karen was a *very* emotional thing. I mean the both of us were really crying from our depths. It was really *hard*. But I *needed* that. Because Karen was, I guess, the focus of bringing back all of the memories about Tasha that I had shelved for so many years.

As the memories started coming out I started feeling *very* depressed. I was getting very depressed, I was feeling very ill. This was only about 2 years ago. Because this particular memory, and thinking about her being euthanized, had *never* come to me. I *never* thought that that was a possibility. It was just more about the loss, and how bad that was, and how hard that was. And maybe the memories had been *nagging* me over the years. I think there was a sense of feeling that *something* happened in there that wasn't very good. *Generally* I shelved it. But there *must* have been *something* that didn't feel good. But I can't really say that I ever thought, *gee*, that was a bad experience, and gee, they didn't treat my child very well. But it *must* have been *there, somewhere*. It must have been in there for it to come *crashing* in like it did when I read "Honored Babies," and later when I talked to Karen.

But I felt *very* depressed when those memories came back. I almost felt like I was having a post-traumatic stress disorder type of thing going on. I'd have attacks of apnoea at night, and wake up without breath. And I also had some periods of feeling palpitations and just feeling *ill*. And getting in touch with this experience, or that memory, coincided with starting to work in childbirth. And because of the nature of the work, it brought up some of these emotions, and I'd be thinking, "*How* are you going to do this work?! How are you going to do this if you're falling apart like this, you can't be like this, you've got to be stronger, you can't be like this!" But I think I needed to go through that. *Now* I feel fine. But I remember driving one time, and then kind of this *memory* of Tasha lying in the corner... *blue*... came into my mind. And I started getting sweaty, and my heart started pumping, and I'm thinking, "What is this? Go away, go away! I'm driving! I'm on the freeway, I can't do this, I can't have these kinds of thoughts and things going on in my mind, and panicking!" *Oh*, God, that was *really* hard a couple of years ago. *Really* hard. Um... and it was *weird* and it was *confusing* to me. I was thinking, "Are you creating something? Just 'cause you've gone on Paula's Honored Babies list, are you trying to create something because these women have *something*, and you came on this list with *nothing*? Feeling like you're going to support them all. And then look at you! Look at you! You're falling apart! What's going on here?" I was *very* confused. And thinking to myself, "Are you creating this?" But then I realised,

"No. It's coming back. The memory's coming back." But I do feel it's kind of passed now. It's almost like... you've got to go through it.

§

Life is so complicated. You can't take one thing, there are many things that influence what you do. But definitely, *that* particular life event, Tasha's death, set the course of my life on a path that has caused me a lot of struggle, and a lot of unhappiness. *Yet*, among that struggle and unhappiness there are still a *lot* of bright spots. And I feel very blessed in my life. *Now* I feel stronger. And, *mostly* I would say that change came with Tatiana's birth 6 years ago. That was such an *incredibly* empowering birth. That birth is *mostly* what motivated me to pursue a career in childbirth. I hired a midwife, and *finally*, got treated nicely as a woman in birth. I got nurtured, and thought.. "Okay, I'm feeling better, I can do this, and I'm going to help other people."

§

I've *tried* to know Tasha spiritually over the years. But I've had difficulty, I've had a lot of difficulty. My husband feels very close to her. But I feel less... I guess I do feel a sense of guilt sometimes, a sense of her feeling that I may have abandoned her. Um.. that they started to withdraw *any* means of support and even compassion. I mean, *my* sense is, if she was beginning to die and they were *proper* attendants, they would have wrapped her up, and somebody would have been sitting in a rocking chair with her and that's what I would have come in to see. What I *did* come in to see has been a very difficult *memory* for me, because *I* feel like I abandoned her to that, to go and get a few hours of sleep and something to eat, and.. you know, it's ah... *Someday*, I, I hope to meet this child and explain this to her, and she's heard me relate this story, if she can hear me, she's heard me relate it several times to a few different people. I guess I feel that's something that I want to work out with her someday, and I don't *feel* that we have worked it out. *Likely* when that day comes, likely it will be instantaneously worked out, is my hope. And I guess I have that sense of.. you know, I really do want to.. communicate with her. I *don't* feel a sense of communication. I know my husband says he does, through prayer. I don't. I would *like* to. But I often go to the grave site and look up at the sky, and go, "Where are you?" You know. "Where are you?"

§

*I have been thinking a lot about death this past year, as two people very close to me have been near death... While I have been alongside, supporting these two people, Tasha has been in my thoughts a lot. What is life all about? What was Tasha's life about? What was her struggle about? Why was Tasha's struggle so short, while others struggle so long, some for a wonderful outcome, others for death in the end, and not always an easy death?*

*I can't say that I have found any answers, it remains a mystery, and maybe that is what I have to accept, that there are things in life that are a mystery that will only be revealed to me*

*upon my own death. I have learned, though, that life is filled with a myriad of incredible thoughts, feelings, sensations and experiences. Some are wonderful and great, others dishearten and sadden me. But, this is life, and I will experience it all.*

*Thank you, Tasha, for always being in my thoughts and helping me think deeply about life and death. Your love and courage stand above all in my thoughts about you.*

*Memory Eternal,  
Your Mother, Sharon (2003 tribute)*

*§*

*Sharon and I sit in armchairs in a cozy coffee shop nearly 3 years after our first interview. She holds a draft copy of her story in her hands, pointing out editing changes she has marked for me. A week ago, she sent an e-mail saying that she had read her story from beginning to end. She said she was moved by it and cried, but "it was a good cry. Doesn't make me feel badly, depressed or anything like that. It just was a sad event in my life and deserved some tears. But I don't feel like I have to hang on to the sadness..."*

*I'm not entirely surprised by the emotional peace implied by her comments. A few months ago, we corresponded by e-mail following the 20<sup>th</sup> anniversary of Tasha's death. In her yearly tribute to Tasha, Sharon spoke of the changes she has experienced recently, which she explained further in our e-mail correspondence that followed:*

*This year I have come to a new place in my thought and consciousness. It has brought me much inner peace and joy. After 20 years the emotions of sadness, grief and anger have definitely become watered down, but I know that I no longer need to carry these emotions, even the watered down ones. I honour Tasha's life, her journey and what she taught me, and I release the emotions that no longer serve any purpose. Thank you, Tasha. (2004 Tribute)*

*...I don't really know how to explain this newfound peace and joy. I just made a decision that I didn't need to feel grief anymore about what happened. What happened, happened, I can't do anything about it and a lot of life can go by grieving, which will not change much. I think I did need to have someone "hear" me, which didn't happen shortly after Tasha's death. I can't say it was a good thing to keep it bottled up for so long. Speaking with you, with others on the internet chat group, and meeting Karen seemed to fulfill the need to share. I feel really "done" with the need to share. I will still share if someone is really interested, but I don't have that feeling of needing to find someone who will listen to me.*

*I can't help thinking too that when one hangs on to grief for a long time that they are suffering from depression. Grief is a thing that just fuels depression. I think, now, that someone who insists on hanging onto their anger and grief is very depressed. I have gone through my times of depression, but I do not wish to be in that place. I know... there are many causes of depression which people cannot "help," but I also think some people have a choice about being depressed and they can bounce out of it if they want to. Some stay there because it's comfortable or because it gets them something they need...(November 2004 email)*



*Sitting across from me in the coffee shop now, Sharon explains a bit more about her perspective and how her grief has changed since she told me her story. She says she doesn't feel the emotional attachment to the memories any longer. She has released the feelings attached to the euthanasia memory in particular, and feels at peace with what happened. Part of the change has come about through new spiritual pathways she has begun exploring. She speaks of the idea that we create our own experiences to some degree, in that if we view our lives in a negative light, it is difficult for anything positive to thrive and grow. In her case, she wonders if the trauma symptoms and resurgence of grief when she began going into the euthanasia memories with Karen were created by her to fulfill her desire to be supported, nurtured and shown compassion, needs which had previously been neglected. I'm intrigued by this possibility, but tell her that I think, too, that it was likely necessary for her to fully acknowledge and experience the feelings attached to the "shelved" memories before peace could be found. Sharon agrees, but again says that she wonders about what she was getting out of it for herself – that the "drama" of the renewed grief and trauma symptoms was a creation of hers that served to satisfy her craving for compassionate acknowledgement of what she and her daughter had gone through. She agrees that perhaps the "creating" or "making up" of the renewed grief was unconscious. Watching and listening to Sharon speak, I'm aware of an aura of certainty, confidence, assertiveness, and peace about her that was only beginning to show in our previous meetings. In any case, she says, she has let go of the "drama" of a few years ago, and she chooses to live a joyful life now instead of one filled with sorrow and anger.*



## 7. JUDI

I feel my son around me all the time  
I still try to protect him  
I feel him with me  
I feel guilty  
I'm always apologizing to him  
for killing him  
he cannot rest  
I won't let him rest  
he's with me, but he's there to remind me  
that I did wrong  
I.. murdered.. my child  
That's why he's with me  
He's there as a constant living spirit  
He will never go away  
I won't allow myself  
to be very happy  
because of what I did  
because he wasn't given a chance for happiness  
I had some control  
I should have done a better job

8

*I push open the steel doors of the sprawling university building and step out into the cold night air. I take a deep breath to clear my head, but it doesn't have any effect. I've just completed my 6<sup>th</sup> interview, and the thoughts and emotions are spinning around in my head. Walking the short distance to my car, I remind myself that of course the interviews were going to be tough. I knew that when I started this 2 years ago. I knew the stories would be horrific. I knew grief would be palpable, even decades later. But I had hoped to find glimmers of hope, peace, and maybe even growth. Not in this mother. I start my car, letting it warm up while I try to encourage myself, pushing myself to look deeper. Maybe I missed something, maybe, maybe... I just hope she's going to be okay, I tell myself as I drive away.*

*I write in my journal as soon as I get home, even though I'd much rather crawl into bed and forget everything. "These stories are horrific. I was hoping to find something positive tonight, but it seems the longer it has been since the loss, the more horrific the story and the more painful their lives have been since the loss. Depression, suicide attempts, multiple reproductive losses. Years and years of self-hatred, self-blame, shame, and anger. No peace, no forgiveness*

*of themselves for whatever imagined wrong they did against their child. Grief buried as deep as it can get. Raging grief that never ends.*

*This one was tough. Mostly I felt like shaking Judi by the end of the interview and saying, "It's not your fault!!! Be angry, hate the doctor, grieve for your baby, but for God's sake, FORGIVE YOURSELF!!!"*

*And then I remember the indescribable guilt I felt before I talked to a friend, who also had a stillborn baby, about the issue of not going to the doctor at my first suspicion that Jacob's movements had reduced. And I understand that if I hadn't had that blessed conversation, I, too, could have blamed myself for killing my baby for the rest of my life. And I feel Judi's pain, but I can't help her. I pray that she finds peace. I pray that they all find peace."*

80

Judi's story is an unbelievable and tragic one filled with feelings of intense anger and unwarranted self-blame that are almost as powerful today as they were at the time of her of her baby's death. Our interview took place nearly 26 years after the death of her 9-hour-old son, Christopher-John (C-J). Judi's grief and her experience continue to play a central role in her life. They are woven into the fabric of the person she has become. She views her son as the focal point of her life, and everything before and after his death is viewed through the lens that she took on as a way of making sense of his death (the "I failed as a mom. I killed my son" lens). Her unchanging grief has clearly contributed to the mental illness that she is now dealing with. Her entire being, *who* she is now, is saturated with that experience and the meanings she has made from it. As unique and painful as her story is, it is an essential part of understanding what long-term grief can look like following a perinatal death.

80

When I was 21 years old, things started to go very strange. I was on a *very* strict diet, and I didn't lose a *single* pound. My periods kept coming. One day I was sitting on a bus, and I can remember the *instant* it happened to this day, with my eyes closed. It was the number 1 bus and I was sitting on it outside The Bay. And I got really dizzy. And *really.. not.. feeling good* at all. I thought, oh, wow, there's something not right going on here. I didn't have a regular doctor at the time. I was only 21, what did I need a doctor for? I was working full-time at a decent job, and living on my own. So I got hold of my girlfriend and said, "Look, what doctor do you go to?" So she sent me to this particular doctor. Which was the *worst* mistake of my life. Because I will *always* blame him for the death of my son. Nobody will ever convince me differently. I went to him, I explained to him that I *wasn't* feeling good, that I was getting *dizzy*. My periods had continued, but he *knew* I was only 21, he *knew* I was sexually active. Would you *not* do.. **some**

*kind of test?* He didn't even examine me. He was very much into psychology and psychiatry, and at that time, everybody had a mental problem. Unfortunately, at that time I *didn't* have a mental problem. I should see him now! And ah... I went to see him, told him what happened. He said, "Oh, you're just under stress. Go home and take this Valium."

Two months carried on, and I was getting worse and worse and worse. I went back to him, I said, "*Look!* I'm *really* getting dizzy, I'm really getting tired! I am not doing well at all!" I had not *lost* or *gained* a single pound, and yet I was on a strict diet. And I wasn't cheating. I said, "I'm not losing any weight, I feel terrible, what's going on here?" He said, "Well, did you try the Valium?" And I said, "Well no, of course not!" He said, "Well okay. Try this." Again, *no* tests, *no* examination, *no* proper history. *Nothing*. He just assumed I was hyper and it was a mental problem. So, I went home. And ah... started taking the Valium. About a week later, I remember I worked a 7 to 2:30 shift. Now, previously, I'd been drained, exhausted after working for 8 hours. That day, I went home, I took my dog out for a walk, I brought him home, I washed and bathed him – and it was a big dog – I weeded my garden, I washed all my floors... I was burning energy, just *burning*, crazy. Just.. off.. the roof. So I decided, "Well okay, maybe I'm feeling better, maybe this stuff is working!" 'Cause I've got all this pent-up energy releasing.

And then, after I came home from work one day, water started pouring out of me. I went into the bathtub until it was finished. And I phoned the doctor and I said, "Um.. there's water pouring out of me. What is this drug you're giving me? What's going on here?" He said "Get in here immediately. Don't come to my office, come into Emergency." I have a problem even walking through that hospital to this day. And ah... I was on my own, so I phoned a taxi. A taxi brought me in. The doctor came in, and checked me over, *for the first time*. And he said, "Oh, by the way, you're pregnant. I think you're baby's coming today." I was three weeks away from my 22<sup>nd</sup> birthday. And I'm laying there, totally alone, with this.. *idiot* doctor.. who finally decides, after seeing me for a couple of months, no examinations, no nothing, that.. gee, maybe I'm not a mental case, maybe I'm pregnant! Duh-h!

So they checked, the heartbeat was fine, everything was fine. They said, "It's going to be tiny. 'Cause we think he's early." *O-kay*... So I was admitted, of course. And the labour was just so-so, barely there. And then it stopped. So they had to induce it. Because all the water was gone, there was nothing else they could do. We're talking 1976 here. There was *nothing* they could do. This doctor didn't even want to give me the blocks! [medication to block the pain] He thought maybe I could just pop this kid out, straight, no problem. This man just was not tuned-in to what was happening.

When it was time and ready to go, I was actually happy, 'cause I had always wanted a family. I didn't care that I was on my own. This was *great*. I was so *happy*, I *really* wanted my son. I was *instantly* in love with him, even though he wasn't even born yet. I was like, "Okay, the guy screwed up, but hey, I'm going to have a baby out of this though. Who cares!" My son was born. And he weighed... 4 pounds. Barely. And ah... I heard him cry, they got him to cry. He was born alive. And I was smiling, I was happy, I had tears of joy, I thought everything was fine. And then they wouldn't let me have him. And they said, "Oh, we're just going to clean him up and check him." And the next thing I know, they said, "Your son's very ill. He's probably not going to make it. By the way, his lungs are solid tissue. Hyaline membrane syndrome." And the only reason he lived for 9 hours is that he had a tiny hole between his lungs where air was actually going through the system enough to keep his heart going. See, now there's some kind of machine that works for them, and so babies don't die of hyaline membrane syndrome anymore, or they very seldom do nowadays. But that didn't exist back then.

They got a paediatrician to take over the baby. 'Cause by this time, I didn't want the other doctor touching me, I didn't want him *anywhere* near me. Just keep away from me, you know, "You've *done* this. I went to you for help, and this is what *you've* done." I did all I could do. I didn't know anything else was happening! And ah... I was 154 pounds when I got pregnant. The day my son was born I went down to 121. Have you ever heard of a woman losing almost 30 pounds while she's *pregnant*? I did. Because the little I *was* eating was going to my baby. And... he was starving. If the doctor had just said, "Look, I'm going to run some tests... Hey, by the way, you're pregnant. This is what you're supposed to be eating." Then I wouldn't have been starving myself trying to lose weight. Very, very weird situation. The rest of the hospital staff *knew* the doctor had mucked it up so bad, from the very beginning. I think they were more concerned with a lawsuit than anything. And I think if I had been stronger then, emotionally, and if I'd been older, I *would have* laid a *major* lawsuit. But I wasn't strong enough, and I was alone, and I just hung on.

We got a minister to come up, and he christened my son before he died. So he died with his name. The staff didn't offer it as a suggestion. I *demand*ed that he be christened. I demanded it. They had him in an incubator. And I had just given birth, *naturally*. And I *stood*, *stood* by his incubator, with my hands through the sockets, touching him. I'd just given birth for God's sake! And I'm *standing*! No *chair*, no *stool*, no *rocker*, no *nothing*. I stood, holding his hand and talking to him, for 9 hours. Until he died. The only time I ever held my son in my arms was *after* he was dead, and they didn't even give him to me quickly after he died. I was able to talk to him though, before he died. When I was talking to him and holding his hand, his hand *grasped*

mine, and he looked at me straight in the eyes. And I'm thinking, you know... God's telling me something. You know, that... the baby's going to be okay. He's going to be... he's going to be taken care of. He's not going to be alone. And I have to... hopefully believe that one day~...

When he died, I stayed that night in the hospital, *of course*. And then I said, "Look, I can't stand being in here." Because I'm on the maternity ward with *all* these other women with these *crying babies*, and *nursing mothers*, and people coming in with flowers and balloons. At that time they had four women to a room. And I'm laying there going, "Excuse me. My *baby's* dead." So they moved me to a private room, and they said I wouldn't have to pay for it. "Oh jeez! Thank you very much!" They kept me in there and I was released the next morning. I told them I had to get out of the hospital. And I went home.

My parents came home with me, just to make sure I was okay, and they settled me in. And then they left. And I was alone again. They didn't even stay one night with me, I was... alone. All the time. I did have Mom and Dad do the funeral arrangements. I was, number 1, too weak to deal with it, and number 2, I was emotionally destroyed. So my parents took care of the funeral arrangements for me. I told them what I wanted. And they did it, arranged it for me. I *refused* to see my son, when he was dead. After I had held him in my arms at the hospital, I refused to *see him* in the casket. Ah, so the casket was closed, and we did a graveside thing, we didn't do anything more. I mean, who was there? There was me. And my mom and dad. And nobody else. I didn't invite any others. It was something that happened so... *irrationally*. And I tell people, and they say, "We've *heard* of things like this happening, but it doesn't *really* happen, does it?!" Trust me. I'm there. I've been there.

§

*"So that's my little story." Judi says as she reaches down and picks up an envelope sitting on the floor by her feet. "Wow," I half-whisper, stunned by her surreal story and searching for something meaningful to say. I know there is nothing I can say in this moment to take away her pain, her bitterness, her ongoing grief.*

*"Every year on his birthday I think of my son. Every single **day** of my life, almost every single minute of my life my son's with me." Judi lets out a quiet, bitter laugh. "Ah, I spend a lot of time up at the cemetery. He's buried in the baby section, one of the old baby sections. And ah... I'm out there at least once a month. Sometimes more often. And I make special arrangements for his.. grave. And ah..." Her voice trails off again with a soft laugh, covering the emotion that is bubbling beneath the surface. Judi has kept a tight control over emotions, her obvious pain veiled with anger, sarcasm, and bitterness in her voice as she has told her story to this point.*

*She takes two small photos from her bag and hands them to me one by one. "I've got um..... of course I, I don't have any pictures of him or anything of him when he was alive. My mom and dad took these two. This is the one in his coffin. And this is in the funeral home. And I never saw him like that. That's, that's the only record I have. You can tell by the flower baskets how **tiny** that coffin is. He was only 4 pounds. And they say, by his development and that, he was just finished the 7<sup>th</sup> month, I had 2 more months to go. So he was 2 months preemie... You know."*

*"Oh-h.. mmhmm.." I whisper, feeling the sacredness of the photos as I look down at them, images of a tiny baby dressed in a christening gown and lying in a white casket. I hand them back to her gingerly. "So.. you said you didn't want to see him in the casket. So how is it having.. pictures like that? How does--, are you glad you have those, or~?" I know that as disturbing as it is for outsiders to think about taking pictures of a dead baby, it is usually something parents desperately wish they had if they didn't have such an opportunity, which was a common problem in past decades. I'm glad for Judi that her parents thought to take the photos, but realize it's presumptuous of me to think she cherishes them as much as I cherish the photos of my son, given her refusal to see her son in the casket.*

*"I'm glad I have them, but I'm also glad I didn't see him at the time. I don't think I could have held together. I, I.. think I was smart enough back then to realise that I was a mess. And.. my parents didn't push me to do it. And ah.. I'm very much an independent person, on my own. But I did ask them to make the arrangements for me. Because.. I could not go down to the funeral home and pick the casket, go to the florists and pick the flowers, talk to the cemetery in the city and decide which plot I was going to get. I just, I just couldn't deal with it. So they did that for me. They also took the only record.. of what he looks like. And it's not.. **the best**. But it's something."*

*"mmm, yeah-h.. exactly." I can't help but think that beneath Judi's words, she thinks she **should have** been able to take care of the arrangements on her own, but was too weak, 'a mess' in her words. That her independence should extend to such a time in her life is unthinkable to me. But I suspect, from how she has talked about herself so far, that complete independence is something she has expected from herself for a long time.*

*"And... I kept all this. You know, um....." Judi opens the tattered envelope, taking papers and mementos out to show me. "I have our wrist bands, from the hospital. I have receipts from the funeral arrangements. I mean, this is what I've kept, because I have absolutely **nothing** else at all."*



*"That's all you have, yeah.. yeah.." I say, familiar with Judi's bitterness, the feeling of injustice that all we are left with of our children is bits of paper and plastic.*

*"Um, I've got his birth certificate. I have his.. death certificate." Judi pulls each item from the envelope as she names it, her voice sounding more shrill with each item, carrying a sense of 'this is all I have and it's not fair.' "Like this.. **was a baby**. That's all I have, I have **absolutely.. nothing else** from my son. I was never given a chance to play with him, I was never given a chance to hold him when he was alive."*

*"mm, yeah-h, yeah.." I swallow back a lump in my throat, sensing the pain and utter defeat in her voice. I am struck by the intensity of her grief so many years later, that she would still think of her son "almost every single minute" of the day and visit his grave so often. While such intense grief is well known to me at 2 ½ years after my son's death, I had expected and hoped that the intense, agonizing grief would subside over the years. Not for Judi.*

§

I do blame myself, inside. But.. I'm sorry, I blame the doctors more. Because.. I was young, and I was screaming for help, and nobody was listening. I think what happened to me scared the doctor, he was scared for his career. When I laid on the table, having just given birth, I was crying with tears of happiness. And he said, "What are you crying for?!" I said, "Because I'm happy. I have this child, I have my son." He said, "Oh." And I said, "Yeah! That's my 4 ½ pound *mental case*. That's my illness. Right there. You made a mistake." And I said that to him. And he's never talked to me since that day. I'm hoping that's one man that burns in hell. He did me wrong. He *doesn't* deserve to be a doctor. Like I say, if that happened when I was older, I would have been mature enough to launch a lawsuit and he wouldn't be practising now. And I'd be filthy rich. Or if I'd been older when it happened maybe my son might be alive. Because I would have known better too. And I blame myself, but I don't feel I killed my son. I feel *he* did. I mean, I *went* to him for help.

At the time he was born I was very aware of the stigmatism of being an "unwed mother." "Oh, God forbid!" you know, like, "Oh, she's one of *those* girls!" I was one of "*Those*" girls. So.. *fine*. In the hospital, the nurses were kind, but they couldn't understand *why* I wouldn't want to be in a room with other women and their babies! There was no thought of that, of that kind of stuff back then. There was just, you know, pop a kid out and go. And there's no way in God's green earth, having no prenatal care *at all*, that I should have gone through this delivery and then they actually let me go, the next morning! *Less* than 12 hours after I delivered! And no follow-up at all. Nothing at all. And I could have had serious complications. They were *lucky* I went away *very* quietly. And I think that's all that they were worried about. I *hope*.. and I pray to



God everyday, that they haven't done something like that to somebody else. I'm hoping it was just a *bad* set of coincidences.

I went to the doctor for help. I was screaming for help, but it was all put down to me being a head-case. I was nuts. I ended up *being* nuts, but I wasn't then, at that time. I have to be almost *brazen* about it, because I *have* to be strong. Because... I have... attempted to commit suicide... over this before. And, ah.. I've been fairly unstable about it. But I'm better now. I'm under the care of a psychiatrist, for my bipolar, or manic-depression. He knows about my son, but we've *never* discussed any of this at length. I don't think he understands the background. My current doctor doesn't have a connection with me about this because I wasn't seeing him until much later. So he can't relate to me on that basis. I had other issues that my psychiatrist was dealing with. And I talked to an R.N., my caseworker, I've told her a bit about it. But not *in length* like this. I've never talked to anybody about it in depth.

My husband knows. Of *course*. He was told that the *day* we started dating. Because I'm thinking, this is not something I'm *ashamed* of. I'm sorry, *yes*, I was an unwed mom, but that's my baby, I'll love my baby 'till the day I die. So I did tell my husband about it. He supports me by coming with me to the cemetery. But he cannot support me in grief. *Nobody* can support me in grief. I haven't talked to my husband in detail about it. He's not the type that would want to. He's comfortable enough knowing I had a baby, it wasn't good, it died.

§

*"What's it like for you though, not being able to talk about this with anyone, or.. have you just chosen not to? You don't feel a need to.. be supported that way, or~?" I'm troubled that Judi has been suicidal over her experience in the past, yet has not opened this door to anyone before in any kind of depth, including her psychiatrist and her husband. Does her fierce independence extend to thinking she should be able to cope with this on her own?*

*"I haven't talked to anyone about this before because... I feel that people can't understand. 'Cause.. people who've not gone through it like **you** have.. and other parents **like** me.. say well.. 'You were an unwed mother.' That's.. the **big** stigmatism. And then it's like, 'Well didn't you know?!' Like they can't understand that you.. some women still carry on having periods! It.. **has**.. happened! It.. **does**.. happen!" Judi speaks slowly, emphasizing each word. "And they think that--... I don't know, I, I get the feeling that when I tell other people, they blame me for it, and I blame myself enough... I don't need other people's.. **judgement**, and I don't need other people's **blame**."*

*"yeah, yeah.. we all blame ourselves, even if there is no reason to blame. And you don't have any reason to blame yourself either, but.. but you feel that anyway." I try to normalize these*

feelings for Judi, wanting her to know that she is not alone in her self-blame, that many other bereaved parents feel this way.

*"But I was his **mother**. **Who** was going to take care of him but **me**? I failed that. I failed in my **prime** responsibility to my son, by not providing for him. ...So, I **am** to blame.. in part.. but I don't need other people putting **judgement** on me, in whether I did the right thing or the wrong thing. I can't un--, I can't change what happened. And.. if it happened again I don't know.. if I would even **know** there was a difference."*

*"No. Of course not, no. It's not your fault," I say. While the judgement Judi expects from others **could** be real, it seems that the greatest judgement being imposed on her is coming from inside herself. I want to take Judi's feelings of guilt away, but I feel like my comments will fall on deaf ears. She has felt this way for so long that it's going to take more than a few reassurances from me to release her from the death grip of self-blame.*

§

I don't trust myself,  
I don't trust anybody else  
I second guess *everybody*  
I just don't like being judged  
by others who.. cannot ever  
*conceivably* understand  
'Cause even if their child dies  
as a toddler, or as a teenager..  
they had *some* time  
They've got *toys*, and *clothes*,  
and *memories*...  
I have *nothing*.  
I have an envelope  
of keepsakes  
and memories of me touching him  
through the incubator  
and holding him when he was dead  
Those are memories?  
Those are nightmares!!

And who can understand it?  
It's been so long, it's been 26 years  
And people are saying,  
"Well *get over it!* Go on with your life!"  
Well.. I'm *trying*.  
But how can you get over something..  
that you *never* really got  
but you *can never get back*?  
I *touched* it.. for *seconds*.  
And *snatched* away.  
9 hours.

What's 9 hours?!  
9 hours is.. is a *life*.  
But *not* a life..  
And too short.. of a life..  
And a death.  
What is 9 hours in a person's life?

The grief is always there  
there's no getting away.  
You can cry yourself silly,  
and the grief will never stop  
There's nothing you can do about the grief  
It's ripped my heart out  
and choked me  
and thrown it away  
That's what it's done to me  
I'm empty inside  
because of him..



*Judi pauses to take a sip of tea, and silence descends on us for a moment while we mull over our thoughts. I've felt a wave of overwhelming sadness as I've listened to her talk for the past several minutes. I think of the isolation she must feel, given her belief that **no one** can understand what she has gone through. Her grief seems to be not only **unending**, but also **unchanging** over the years, raging on as intensely as ever. I'm left wondering whether she sees any possibility of making sense of her experience enough so that she can find the peace that has been so far beyond her reach for so many years. As Judi places her mug back on the coffee table, I ask, "You say the, the grief, just--, it doesn't end, eh? How do you.. have you come to any way of making sense of it for yourself?"*

*"... No, a lot of it is still placing blame. I do a lot--, well, you've heard. I do that a lot. I have to place the blame, but I place it on **me** first. You know, **I** am the **one** to **blame** the **most**. And... I, I think I **torture** myself, in some ways? 'Cause I won't forgive myself.. for letting it happen. I don't forgive myself for not standing in and protecting him... And, I **know**.. when you look at it from the outside looking in, I **know** it's **stupid**, because I had **no** control, I **went** for help."*

*"Exactly, yeah, yeah.. it's not your fault, but that's how you feel, it's not a rational thing you can easily talk yourself out of." I'm relieved to hear Judi recognizes the irrationality of her self-blame. I suspect that no matter how many times I tell her she is not to blame, it will not significantly change how she feels. Somehow, she needs to find a way to forgive herself for a crime she didn't commit, and she knows this but just doesn't know how yet. I vividly remember*

*the months of unspeakable guilt and shame that I felt after my son's death. I can't imagine feeling that way for 26 years.*

*§*

*Myrna & Jacob: "Do you think we could have saved him if I'd come in sooner? He never moved a lot, but he was moving even less in the past little while, and I thought it was just because..." I'm still reclined in the birthing bed, talking to the doctor as I wait for the nurses to bring Jacob to us after cleaning him up. I'm consumed with thoughts of whether I could have saved Jacob. Dr. S has already started to shake his head before I finish my sentence, a pained expression on his face. "Don't think that way.. there-, he had much more serious problems than we ever knew. I don't know why the second ultrasound didn't tell us more, but he had serious problems, much more than a cleft lip." He seems caught up in his thoughts for a moment, and then he goes on to discuss details of meeting with the geneticist and other things I can't focus on. His reassurance registers with me, but my heart doesn't believe it. No, I could have done more, if only I'd gotten checked out sooner...*

*I sit in my family physician's office with my chair pulled up close to hers, our knees almost touching. It is 4 weeks since Jacob's birth/death. She is showing me the autopsy report, and explaining the various medical terms and the numerous birth defects they found in Jacob's little body. "Do you think he would have survived if we caught it in time, if I'd gone to the hospital sooner?" I ask, desperate to be told it wasn't my fault, that there's nothing I could have done to prevent his death. She has been so kind, visiting me in the hospital while I was in labour even though I was not under her care during my pregnancy. If anyone can give me the forgiveness and peace of mind I'm seeking, it will be her. "I'm not the best person to ask, but my guess is that the combination of heart and kidney problems would have made it touch and go for him.. Ah.. even if you'd gone in as soon as you noticed less movement, well.. only God knows the answer to that, and doctors always wonder the same sorts of things about their own roles in these situations. But you know, even if you don't get a definitive reason for why he died, at least we know he had a lot working against him, unlike some babies who are completely normal and still die, with no known cause..." As I leave her office building 20 minutes later I still hear the nagging voices of guilt. Her answer has not cleared me of my shame, the feeling that I let my baby die inside me and did nothing to save him. I was the only one who could have protected him, and I didn't. Why, why, why didn't I go to the hospital sooner? It's hard to breathe with the constricted feeling in my throat, my chest, my lungs... my soul. I hope I can forgive myself someday.*

*§*

The blame  
I can't get rid of the blame  
and the guilt  
And the **hatred**.. for that doctor  
If there's anybody in this world  
I would like to **kill**, and be **allowed** to kill..  
I would make that man go through so much torture  
I would have him **screaming** in pain  
for **hours** before he died...  
I would dearly **love** to kill that man  
That's how much I **hate** him  
for being so **ignorant**...  
of what he was doing  
to a 21 year old girl.. and her baby.  
'Cause.. he killed my son...  
and he partially killed **me**.  
'Cause he killed me spiritually.....

§

"I just wonder **how** many other doctors are out there like that. You know, with, with the-- ... medical situation that it is, everybody's so busy, waiting lists are so long... what else is **really** going on? **Who else** is being left through the loop? See now it's because everything is so busy, they, they recognise it, but there's no.. no help. Back then, people wouldn't even **recognise it!**" Judi takes on a mimicking voice. "I was a **dirty little girl**, I had a--, I had an unwed--, I was an unwed mom! You know! And not only that, I killed my baby! ...Like, I was a whore, plus.. a murdering whore!"

I sigh audibly, a bit overwhelmed by Judi's feelings of guilt, anger, and shame. But I can sense that all she needs from me right now is someone to listen without further judgement, judgement which would reinforce her belief that no one understands. "mmmm... And you got no compassion at all.."

"No...I, I went back to work... **4 days** after I got out of the hospital. **Four days** after my son was buried--, 4 days after my son **died!** And it was like 2 days after he was buried, I went back to work! Full-time permanent! I wasn't **granted** maternity leave."

"mmmm.. And did.. your employers know, did anybody know at work?"

"Yes, they sure did! Well, I had gone from 154 pounds down to 123--, 121! Like, excuse me!" Judi laughs bitterly. "Something happened here! Right? ..I was not permitted maternity leave. And they said, 'Why? You don't have a baby.' ..Well I **had** a baby. 'Well, yeah but you--, you can go back to work, you're not doing anything else. Right?' No maternity leave, and yet I had gone through a **pregnancy**.. and a **delivery**.. and a **major death**. I should have gotten **bereavement** leave! None of that. None of that. My, my son only lived for 9 hours, what do you--

, what do you need bereavement leave for? So my employer was really bad about that, I got absolutely nothing.”

§2

The first day I walked back into work, one of my supervisors said to me, “You know, I kind of wondered a few weeks ago if you were pregnant.” And I looked at her and said, “Why the *hell* didn’t you say something? You’re the *only* one who *suspected*. Everybody knows I didn’t know.” I said, “You couldn’t.. for once.. have *said* something?” ...And I just walked away from her. And I told the head supervisor, I would not work under that supervisor anymore. And ah.. one of my friends was in the maintenance department, and he had actually come to me in the hospital that night, and comforted me a little bit. Because I was alone in the hospital that one night. So he stayed with me for a couple of hours. He wasn’t the father of the child, he was just close to me. And ah.. I walked through his department at work my first day back, and he looked at me, and he said, “My God, you’ve lost so much weight.” How many women have a birth, and lose 33 pounds? Instantly. Go down 33 pounds. Like how many women normally *gain* 33 to 40 pounds that they’ve got to lose?! I would have given anything to have *had* to have lost 40 pounds after my son was born, and lived. I would have sacrificed the weight.. *Please!*

And after that, nobody says anything... it’s just... not *talked* about. When my cousin did the family tree, almost 10 years after my son died, she was going through the list of family members, their marriages, children and whatnot. And she came to me, and I was unwed at the time, so her list had just me, my parents, and my sister and her family in our branch of the family tree. And I said, “Well where’s my son?” She says, “What son?” I said, “You know my son! I want Christopher-John on that family tree.” She said, “Oh, okay.” And she would never let me see the family tree after that. This past May I actually got to see the family tree. And she didn’t put him on. She wouldn’t give *me*... that much consideration. So, when the family tree was waltzing around, I added it. I *added* it, I thought, “Don’t be a stuffed britches on me, *my son was alive*. My son.. *breathed* for 9 hours. He was a human spirit, he *still is* a spirit. Don’t tell me he’s... not part of the family. He’s is just as much as your kids are!” So I got my own back on that one.

My fiancé, the father of my son, died 6 months after I had my son. He wasn’t really involved with anything to do with my son. He was out of the city most of the time. He phoned me one day. And he said, “Where have you been?” ...I said, “Oh I’ve... been in the hospital.” He says, “What, did you have surgery?” I said, “That’s not what I had.” And he *knew immediately*, what I meant. And ah.. he said, “Oh.” ...And then he just... turned quiet, we never discussed it after that, he’s never been to the gravesite, he was not *part of anything* after that. And six months after my son died, my fiancé died. But, it was over *anyway*. It ended as soon as I told



him what had happened. He's never seen these pictures. He's never heard the story. He didn't want to know. It may have been the shock that made him ill. He got very ill about 3 months after I told him. He became very ill and died, and... we just never had a chance to get together, *talk* it out, *be* together... *deal* with his grief and my grief.

I wish I had had... *somebody* to share the grief with. Like this person that I was talking to today, he's actually my insurance representative, who's helping me go through this rehabilitation. He lost two daughters, when they were teenagers. And I told him about this interview with you. But I said, "You don't know the kind of grief *I've* gone through, even though *you've* lost children. 'Cause your children were older." I said, "Plus you were married, you had a support." And I guess when *his* children died, his wife became distant and aloof, and they ended up divorcing. And *he* still has to deal with that grief... alone.

§

*I never had **anybody** to help me deal with it  
It's been my **own** grief  
all the way deep down inside  
I never could partnership it out with anybody  
I haven't looked for other people to talk to  
like support groups or anything  
I've kept it all buried inside*

§

*"What about your mom, your parents – how did they react at the time?" I keep thinking that there has to be someone in Judi's life that she could turn to, that would understand and support her. It's never a safe bet to think that their own parents will be able to support in the way bereaved parents need, but it's worth a try, I think to myself.*

*"My.. mom was very stellar. Very strong... she was more worried as a mother about **me**.. than as a grandmother about my son. See that was.. that was important. But **she** didn't hold him.. ever. I was the only one who ever held him, I was-"*

*"Did they--, they didn't see him except in the casket?"*

*"That's right, yeah, yeah. And ah.. you know, so they had no **bond**.. to that at all. Where I.. did have a **living** bond. And ah.. but my dad – I was really surprised, my dad fell to pieces at the gravesite. He just went **completely** to pieces. And I was really surprised at that. I mean, my dad served in the **war**, and he was a **gruff** old man, and.. my God, that just.. cut him to the quick. I think that, in the end, it affected dad **almost** as much as me. And a lot more than it did my mom. Which is really strange, but... my dad always wanted a son, so maybe that had something to do with it... And see, there are no sons or grandsons in the family. He is the only one."*



"yeah, his grandson... so having that.. kind of grief connection with him then, was that a comfort at all, or~?"

Judi sighs regretfully. "No. I thought it was going to. It just **surprised** me.. that he had those kind of feelings. But then he went back to the way he was.. towards me to **begin with**.. Ah, it was just towards my son, **at the gravesite**, that he reacted differently. I.. but he didn't bring us any closer. No, no."

§

I belong to a writer's group, and we talk about various topics and then we write on them. One day the topic was having babies. And instead of running away like a scared rabbit, like I would have normally have done, part of my own *healing* process has been trying to deal with this. So I wrote about some of these things. And then after you and I talked on the phone, I had a meeting with my writer's group, and I have written about the project we're trying to do here. So, I do write it out. I do air it, I air it in my writer's group. That's who gets to hear it. I've had a poem published, and it's the only formal work I've done on him. And... I just needed to.. honour him. And say like... you know, I was there. I think I would have been a good mom. I, I... I hope I would have been a good mom. I think I would have offered a child a good life. At least I hope I would have.

I can't help but wonder, really. I often wonder what he would have been like. He would have been going on 26 this year. I mean, I think, hell, I could have been a grandmother by now..... And, what would he have been like, what would he have done? He was never given a chance. He was *never.. given.. a damn.. chance*. You know, and I see these people who have, for religious reasons and whatever, *choose* not to help their babies. *Don't* do that! {said in a pleading, sad voice} You know, like.. that's a *life*...

The first few years it was very tough for me just to see a baby... And then when my husband and I were married in 1988, we got pregnant on our *wedding night*. And of course, we were just, "Hey! This is great, we're going to have a baby, we're going to be happy." And then we lost the baby. Before we got married, I had jokingly said to him I wanted six lusty sons. And then when we lost the baby it was like, "Oh... okay... well, we'll have another one." And then it happened twice more. And then it got to the point that I couldn't stand seeing babies at all. I *hate* babies. Can't stand *looking* at them. I really still have a problem. I'm getting better, when I'm with people who have babies and they say, "Oh, do you want to hold the baby?" I say, "No thank you." I can't.. *allow* myself... I see babies, and I want a baby. I *really* want a baby. And, you know, I used to go around, up 'till last year, I was going around saying, "Oh, I *hate* kids, I hate kids." I'd hear a kid scream, "*Ah shut up* you little brat!" ...And.. it was... a defense mechanism

for myself. Trying to deny that I *really.. wanted.. a baby*. And I'm nearly 50, and so... it's *over*. Like there *is.. going to be.. no baby*. So now, it's not a matter of seeing a baby and being *fearful* of having some trouble with having another baby. But now it's looking at a baby, seeing my *own* dead son, and *knowing... knowing* there will *never* be a baby. And people say, "Well why don't you adopt?" I *can't*! Once you have your own child, and you *know* you've got a body that can produce a child, somebody else's baby doesn't work. You've got to have your own baby. At least, *I* need to. You know, and ah.. So, adoption is totally out of the picture.

I would probably have dealt with it better if I *had* had another child. Because the instant I knew I was going to have a baby, I had those *labour* hours to get all *geared up* for it... and 9 hours of *pain*. Of his *death pain*... afterwards. And it's like, I've got all this pent-up *motherhood*. What do I *do* with it?! And that... it's still there. Like, I *want* a *baby*, for God's sake. And then three miscarriages just added to the feeling of having motherhood offered to me and then snatched away. And now, it's just like, just dismiss it, just dismiss it. Just dismiss it completely. And it's actually made such an impact on *both* my husband's and my life that he.. um, became non-performing. We're now seeking marital help, we're going to a marriage counsellor. Because it got to the point he didn't want to *hurt* me anymore, so psychologically *he* shut down. And that doesn't exactly help when you're trying to have a family.

In our marriage counselling, we talk about these issues being the trigger for the problems we're having. But I mean, what can you do about it? You know, it's just part of that... He's doing really good with the marriage counsellor. We've only been there a year. And he's doing *really* well with her. He's finally talking, and opening up, and we are finding a difference. But as far as babies are concerned, we *both* want a baby. *Oh-h-h*, so badly. But we both know it's never going to happen. And... I think *he'd* be happy if we adopted. *I* just can't. I can't bring myself to do it.

§

**Bang.** *My attention is pulled away from my writing by my 14 month old son dropping a toy in the next room. I hear him giggle in that irresistible toddler way as his dad tickles him. Oh man, I'd so much rather be spending time with him right now. These stories are just too painful. It has been hard to get back to the writing since his birth and my maternity leave. I have to keep reminding myself that this is important too, that I really do want to finish, for myself, for Jacob, for my participants. Maybe my great difficulty in spending less time with Caleb in order to write has to do with not wanting to miss a second of his life, because I know what it was like to lose all of Jacob's life.*

*I feel a stab of guilt, reading Judi's comments about her pent-up motherhood, her lost hope of ever having children now that she's nearing 50. What do I have to complain about? I feel guilty, but also so grateful to have had the opportunity to have another baby. Why was I granted this opportunity? I am no more deserving of another child than Judi is. Where would I be in my grief now, or 20 years from now, if I was never able to have more children? Thinking of Judi and Deena and their grief over being childless mothers, and remembering the 3 ½ years I spent wondering if we'd be able to have more children, I vow to never take my son and any future children for granted.*

§

*I think now I can't..  
commit complete love  
towards others  
Maybe that's why my husband and I  
have had some marriage problems  
Because there's still part of me  
that's.. not going to get caught again  
I'm not going to allow myself  
to get hurt emotionally  
To love that much again  
As devastated as I was  
It just cost too much*

§

I'm almost afraid to get too close to anybody anymore. 'Cause with my baby dying, then my fiancé dying, within 6 months of each other, it was like... everybody I touch... *dies*. You know. I've written a piece, in my writer's group, where I say that death follows me around like a black panther. And it's true. People I get close to *die*. And I suppose everybody does. But it just seems there for awhile that anybody *really, really* important in my life... wasn't there for me. 'Cause they died. And then I became non-committed. And withdrawn. Shy... Ended up with bipolar. You know. It just affected my whole life. It's just *destroyed* it! I went *crazy* as far as my career is concerned. I *threw* myself into my job. I was an accountant for 9 years. I was working 18 hours a day, 7 days a week. The *first* 3 months after my husband and I got married, I never even took a day off! We were 3 months into our marriage! ...And, then I had the miscarriages. Because I was at work *all the time*. I was totally stressed out. I wasn't eating right, sleeping right, I was just *burned* from both ends. Because I threw myself into my job. Again, it's part of the bipolar, because you get *really* high, and you've got the *energy* to do everything. And then you go into the depression. And then you've got to *do things* to *get yourself out* of the depression. You know, and it's a double-edged sword. Both swings, enormous swings like I have, because I'm bipolar I, it was just murder. I mean, it's.. it was all built up, you know.

The doctors think there were a couple of things that triggered the bipolar. I didn't have a real episode like a lot of people do who end up in the hospital. Um, when I was 7 years old, we emigrated into Canada. I'm British. I'm *still* British, I am *not* Canadian. I'm very proud to be *British*, I travel on a British passport, and that's all there is to it. And I remember the first thing I saw in Canada was the airport, there was a red *barn* by it at that time. And I saw *that* in a *snowstorm*. We got off the plane and I remember turning to my dad and saying, "Can we go home now?" See, I wasn't given a part of the decision. I was told we were coming here for a visit, and we've been here ever since. And the doctors think that's what started the trigger then. And then being short, and very obese like I am, *that* added onto it. I became shy, recluse... and then my *son* died.. then my *fiancé* died... And then I got *married*, and had 3 *miscarriages*... And then I was in a *near-fatal* car accident. Well, gee, if you don't do something after that, you're weird if you don't get weird. It was just too much, I couldn't deal with... all of it.

I was diagnosed with fibromyalgia 2 years after the car accident. They think the car accident brought that on. And I was diagnosed about 3 years ago with the mental illness. I was put on disability in '93, and I think it was '95 or something like that, they discovered the bipolar, and started treating it. So with the bipolar, and with fibromyalgia, and the car accident, we've been working three years, trying to get the medications to stop the *pain*, and get the mood swings to stop. And it's been just the last month, 5 weeks that I'm *actually.. doing.. so-o* much *better*. You know, I'm looking for part-time work, I'm going back to university, I'm feeling better about myself, and... ready to get up and go. And I haven't felt like this since 1993. And it's just because of *one* change of one medication. But like I say, this is one of the things that... I will always.. I, I guess it's the blame.. I, I live with the nightmare of the blame.

I keep thinking, "God, why did you do this to me?" You know, the old saying, "*Why* did you have to do *all this.. to me*? What are you testing me for?" Like, "Why are you testing me.. this much?" I was very... distant from my religious feelings for a long time. And it's only been the last couple of years that.. I'm starting to take some comfort that.... maybe other people had hands in it that I didn't. 'Cause right up to now it's been all self-blame. And.. like I was *abandoned* by God, and I was *abandoned* by the medical field, I was *abandoned* by my family... I was abandoned by everybody! And then it was like, *what* do I have to prove?! Why do I have to keep *proving* things? And especially when we had the three miscarriages. And then my husband became impotent. So there were no children. And it's like, okay.. here's another stepping stone! We lost my son. We had three miscarriages. Okay, we're older, we're wiser, it's a good time to have a child. Then God takes that away from me too. That He keeps.. *offering* it. And yanking it

away. It's more frustration that I feel than anger. Like, I don't understand why. I hate myself enough as it is.... You know. And it's ah.. and I do hate myself.



We had a little bit of a weird ending to it all. Well, it's not even an ending really, 'cause it's still in progress. On my son's grave there's a marble angel, and a marble headstone. My son is *quite* clearly marked. And 3 years ago in the summer, somebody vandalised my son's grave. They took the marble angel off. *Who* knows *how* they did that, because it was right down in, cemented down. And they destroyed five other babies' headstones with *my son's angel*. Not only was *my* son's destroyed, but *my son's* was the instrument of destroying of the other babies' headstones. I went on television at that time, and the media did a story on all the security problems at the cemetery, with lots of vandalism going on. And I went on T.V. to complain *openly, in public* that the security just wasn't good enough. I screamed and yelled in the T.V. camera. Wrote letters to the mayor, wrote letters to the police chief, saying, "*Where's* the security, *what's* going on?" Shortly after that we got the gates. And then we got a security patrol. But it's going to cost me 1200 dollars to get the angel repaired on my son's grave. I own the grave, I own that little chunk of land, it's my property. So if anything goes wrong, "Hm.. too bad lady." See, that's all it's been, all along, through every institution I've ever had to contact regarding my son, it's always been, "Well.. too bad lady." I often wonder, if I had been partnered with somebody – like a boyfriend or a husband – if the situation would have been different.

If I had the choice again, I *would* have my son cremated, and would have his ashes scattered. It is... *very* tough for me to keep going to the cemetery. But I *have* to go, because I'm *responsible* to make sure his grave's okay. I didn't take care of him *before*, I've got to at least do that *now*, right? And so I would *like* to be able to break away from the need to go there all the time. But I can't do that. I can't desert him again. And I feel like... that's basically what I did before, is I deserted him before. I have *tried*, I am going to the cemetery *less* than I *have* done. I used to go up like every other week and spend hours, just sitting beside him. It was... turning my head round. I was **obsessive** about it. **Extremely** obsessive about it. It's was like, on his birthday, his **whole** grave was **covered** in blue carnations from **head to foot**. Five or six arrangements. It was obsessive. I *knew* I had to start cutting back. So about once a month I go up now, but I don't stay. I just lay flowers, make sure everything's okay, and then I *have to* walk away from it. I wish I had not committed him to the earth. I wish I had scattered his ashes so he could have the freedom he always had. You know, and.. like 'cause he's.. in the dark ground, and I~... But back then, cremation was not a *big thing*, it was *rarely* done. And it was something I... didn't do. I never even considered it, nobody *mentioned* it to me, I was in no condition to

think about it. And I **wish** back then **somebody** could have **helped** me **see** that that would not have been a good idea. And now that would be my choice. I would not put a baby in the ground if I had the choice again. Because I made a choke-hold around my neck, I can **never** let myself forget, and never release myself.

But he's got a dog buried with him. {soft laugh} We had a dog, a *big* huge monster of a dog. We had him cremated, and we buried his ashes with my son. So he's there and protected. He's got a dog. My son finally got a dog. You know, but you think of things like that, you think of doing things for your child, even though he's not there. I put flower arrangements up, hoping he will like them. I know going to the cemetery all the time is not healthy for me... But I need to know that there's been no more damage, and that he's okay. But what bothers me about the vandalism most of all is not the damage they did to the statue. But that they *used.. my son's angel.. to hurt* other little babies. They hurt *five* other little babies' graves.

§

*"But, yeah it's.. it's been an interesting life."*

*"yeah-h, a real roller coaster, yeah." I feel exhausted, like I've been thrown around the room by the intense grief, anger, guilt, and shame that have filled Judi's story. I can only imagine how she feels.*

*"You know, like it's, it's, this is no **bullshit**, this **really happened** to me. You know, it's not just like a happy little married couple, and having a baby, and whoops~"*

*"yeah, yeah." I can't help wondering if she thinks my husband and I are one of those happy little married couples, with plenty of support for one another, making our grief so much easier to bear, and making it impossible for me to really understand her experience. Maybe she has a point.*

*"**It's.. been.. one.. hell.. after.. another.** And I think the stress is why I lose the children. Why I lose the babies..... But I'm hoping," Judi takes a deep, shaky breath, "I've been able to **vent**, now. Sorry about that, but I-"*

*"No, that's what we're here for.." My feelings of hopelessness and frustration at her unrelenting self-blame melt away instantly as she says this, reminding me that this is her first opportunity to talk in any kind of depth about her experience. She really needed to vent, and I'm glad I could provide her with that opportunity. I'm humbled and honoured that she has trusted me to hear her story, given her distrust of others and her fear of being judged.*

*"-but, it's like.. okay.. I got it out. It's **out there** now. Maybe I needed to get it out there and look at it. 'Cause all this time I've been.. carrying it around. You know, and, and.. the blame. The blame."*



*"I can't imagine.. never talking to anybody.. about it, you know, or not that much anyway."*

*Judi nods slightly, taking another deep breath before continuing. "But I've always been on my own. See, my dad had a heart attack when he was 54. And.. he's been dead.... since '84 now. And so he was **sick** when my son was born. He was so torn apart at the funeral, we thought he was going to have another heart attack. We were more worried about **him** having another **heart attack**, with what was going on. And ah... so my dad was always very, very ill. And ah... so everybody's been kind of geared towards taking care of my dad. You know, my dad's number one, my mom's always been the number one caregiver, **she** went out to work, the whole bit... My fiancé died. Ah, my best friend.. that I went to university with, moved to England. **She** was in another country at the time! My sister and I are **very, very different**. And we have **never** been close. So, that was not an option. I **had** nobody! My friends were out of the country. Literally!"*

*"Yeah.. it just eats away at you then."*

*"Yeah. And like I say, my husband can **support** me in my grief... but he'll **never** understand it. There's **no-o way** he can. It's **impossible** for him to understand. And.. even my mom can't. 'Cause like I say, she doesn't have any **live** memories. She has the funeral home memories, and she has the funeral memories. Ah.. **but that's it**."*

*"So do you talk about him with your mom?"*

*"Mom and I have never really had this talk. She can't talk about him now, because a year after I went on disability my mother had a massive **stroke**. She is **paralyzed** down.. one right side, **completely**, she's in a wheelchair. She lives with my husband and I. I'm her number one caregiver. I'm the only one who knows her medication 'cause I take care of her. She's also diabetic, I take care of her insulin, her blood tests, the whole bit. So I don't talk to her about this, because she's trying to deal with, like number one, my own dad's death. And.. she had her stroke 3 months after she retired. Age 65 she had a stroke, and that was **it**. And.. she's been living with this, she's paralyzed, and she's had **cancer surgery** last year, she's had **eye surgery**, she's **diabetic**, like.. she's got **enough**. She doesn't need to hear.. me talk about something that happened to me 26 years ago. So who do I have? ....I have **nobody**. I've **always** been on my own. I moved out when I was 19 years old! I lived on my own when I went to university. I didn't even have a **roommate**! Like I've **always.. been.. alone**. And I, I think that's the **bad** part about it. Because.. I couldn't **share** my grief with anybody.."*

*"yeah, you had to rely on yourself."*

*"I couldn't sit down and say.. was I.. **really.. responsible**? You know, like, **tell** me. How.. was, was I **really** at fault? You know.. did I **kill my own son**? I think this is what's doing it. It's in*



the back thought in my head, that **I.. killed.. my own.. child...** And I... I don't know how--, if I **knew** how to get rid of those thoughts I would... I mean, I've been trying for 26 years to come to terms that he's **dead...** he will **never** be alive..." Judi's voice is noticeably shaky with emotion for the first time since the interview began nearly 2 hours ago. "And **yes**, I had a hand in killing him. ....And I've got to deal with that, I've just--"

"mmmm... and you can't tell those thoughts to just go away and they magically disappear."

"No. See, I'll never forgive myself for killing my son. ...**Never**. I'll **never** forgive myself for killing my son"

"Oh-h, God," I whisper, overwhelmed again by Judi's self-blame. "What do you think it would take to.. to forgive yourself?"

"....I.. think.. the doctor coming to me, saying, 'I made a mistake. I'm sorry... Forgive me for what I've done. I learned from it, and I never hurt anyone else like that again.' If he would acknowledge.. that hey! maybe he did something wrong – at least that he was sorry – then I could maybe forgive myself. But as long as I can't forgive him, I can't forgive myself, because I'm the first in line to blame. So you've got to blam--, you've got to release others before you can release yourself. And I don't release him, I'll never release him, until he comes to me, and he'll never come to me. But if I could forgive him for playing a major **part** in killing my son.. I think that would be part of the healing. You know, I kind of... would like to have reinforcement from him.. **promising** me he **never** did that to somebody else again. But.. that's never going to happen. You know, that's just never ever going to happen."

"So since it will never happen, what do you.. what do you do with that then? I mean.."

"Well, it's just like.. blaming myself, and, and knowing that I, I'm a murderer. That I killed my own son."

"oh-h God.."

"It's something I've had to live with, and that's.. part of my illness. It's part of what I've had to deal with. And like I say, now I have to deal with my mom's own illness, and~" Judi laughs as her sentence trails off, and her tone of voice carries a sense of 'I've had so much thrown at me, it's almost ridiculous.' I suspect that underneath the laughter the tears are threatening to break through.

"It's more than one person should have to deal with."

"Yeah. So... I, like I say, I've actually attempted to commit suicide a couple of times. I'm not very good at that either! I'm not very good at having children, and I'm not very good at committing suicide. I'm not sure what I am good at. But--"

*"So when that--, when you attempted suicide then, did... did you go into the hospital, at all?" Once again, I'm concerned about Judi's well-being. I feel like it's essential that she talk with her mental health professionals about her son and all of the feelings she has displayed here for me tonight. It's clear to me that these issues are a big part of her mental illness, and that the medication she talked about earlier is only a partial solution.*

*"No. no"*

*"Okay. So nobody--, is that when you started seeing the psychiatrist? Did you get hooked up with anybody at that time to talk about where that was coming from, and-?"*

*"No. They didn't realise that I was--, that I had a mental illness, until my insurance company got involved with my fibromyalgia, and he and I were talking, and he said.. 'I want you to go and talk to somebody.' So he made arrangements with the psychiatrist that diagnosed me. And then I got hooked up with my current psychiatrist, and **then** things started to roll. But it was--, believe it or not, it was my **insurance** company that got me on the road to healing. Which.. **never** happens. But it--, thank **God**... he was outside of the loop enough, he could see things that everybody else was either ignoring, or **couldn't** see 'cause they were too close in. I **knew** I wasn't right. I know--, I know I'm controlled now. I know I'm okay, I'm getting back my life.. what I **can** get back of it. But, I **can't**..."*

*"you can't get rid of those thoughts that you--, that it's your fault."*

*"The blame. I can't get rid of the blame and the guilt."*

*§*

*I sit at my computer, staring at the screen as I review the transcript of my conversation with Judi. I am saddened and overwhelmed by her unjustifiable self-blame, her grief that is seemingly as intense today as it was at the time of her son's death. Another participant, Irene, whom I interviewed just days before Judi, came to mind often during the interview with Judi, and I think of her again now. Irene's story contained a figurative envelope which keeps popping into my mind as I recall Judi showing me her envelope of mementos. This is only one of the parallels that keeps prompting me to link these two women's stories in my mind as I work to write Judi's story into chapter form. I grab the computer mouse and open Irene's transcript file. Scanning quickly, I decide that, yes, I'd like to bring Irene into "conversation" with Judi.*

*§*

*Like Judi, Irene was a young single mother when her second child, Keirin, died shortly after birth, 36 years before our interview. She had a history of violent and troubled relationships at the time of her pregnancy with Keirin. When he found out about the pregnancy, the father of her baby attacked her with a broom handle, attempting to abort the baby. Irene was in a*

distraught and confused state of mind after the attack, and didn't tell anyone what had happened. For several weeks she wondered if she was still pregnant. Eventually, she went into labour (about 2 months premature), and her baby was born in a bedpan while the staff left her alone at one point. He was alive and was rushed away before she could see him. After the birth she began haemorrhaging and was in serious condition as a result of complications from the attack she had sustained. She was informed several hours later that her son had died. When she cried upon hearing the news, the doctor told her, "**Stop** that. You **didn't.. want.. this.. baby.**"

Irene pushed her grief away, as those around her seemed to expect her to do. The baby was never mentioned, even by her mother while she was still in the hospital. Irene became pregnant again soon after, and had to give up her daughter for adoption at 10 months of age because of extreme poverty. Years later, she attempted suicide and was in a psychiatric hospital for over a year, where she began to process the many losses, addictions, and horrors in her life.

Judi and Irene's stories have some interesting parallels, but Irene's uncovering of her buried grief and her eventual self-forgiveness contrasted with Judi's feeling of being stuck in self-blame and unchanging grief. The comparison between the two women won't leave my mind. Judi said that she hoped her participation would help her, and that she hoped to see how other people were dealing with their grief. "Am I the only one who feels.. some of the things that I'm feeling?... Am I really a bad person, should I be locked away?" Hopefully the peace and personal growth that Irene was beginning to experience can give Judi some answers, and ultimately, some forgiveness and peace of her own.

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**Judi:** *I never had **anybody** to help me deal with it. It's been my **own**.. grief, all the way deep down inside, I never could partnership it out with anybody. I haven't looked for other people to talk to like support groups or anything. I've kept it all buried inside.*

**Irene:** *While I was hospitalised, a lot of your fears and your... nervousness and your psychosis... in my case, anyway, was likened to a lot of boxes tied up with string. Placed carefully on top of each other. And all being kept standing together, and carefully balanced. And as I progressed through being hospitalized these boxes kept falling over and coming untied, and all the monsters, or the monstrous feelings were coming out. But the one that didn't was this other one, this envelope really, not even a box.*

*There was a very kind man at the detox centre that I went to. I remember him telling us that we weren't... stupid, we weren't rubbish, and we weren't... useless. {whispered, with emotion} That had a great **bearing** on me. And he said that all these other things that we had... and that we pushed down, and the **drink** and the drugs, and addiction is **often** a symptom of another thing. In that... it's used as a tool to push down to keep things in place. And the part he said that made such a great deal of sense to me – and I only started thinking of it again when I decided to tell you my story – he said, "No matter how much you bury something, and you keep burying it, and you pile things on top of it, like booze, or **other** feelings, **or** abuse, or*

relationships; you can keep **piling** these things onto this buried stuff, but it's not dead, it's **still.. only.. buried.**" And I realised that, I thought, yes, it's not dead, it is **buried**... And it has to see the light of day.

I have to **acknowledge** that... {crying} I have to allow myself... to acknowledge that Keirin did come into the world... and that nobody should have put a broom handle up me and destroyed.. a lot of my life, as well as his... for so long... {crying} And..... {crying} I think that .. probably.. I felt I had collusion in it...{crying} So that's probably why I buried it.....

**Judi:** The grief is always there. There's no getting away. You can cry yourself silly, and the grief will never stop. There's **nothing** you can do about the grief. It's ripped my heart out and choked me and thrown it away. That's what it's done to me. I'm empty inside because of him..

**Irene:** I sincerely believe that the grief.. never goes away. It's always there. And it cannot be ignored. Because it does affect you. Whether you ignore it, or bury it like I did, or pretend it didn't happen. And it isn't the **fact** of the baby, the **fact** that he lived and died, that's **not** what I buried. It was the **grief** I buried. First I wasn't allowed to grieve, and then I didn't allow myself. And grief unexpressed is... it's almost like a disease, a cancer in a way. Because it doesn't go away, it eats away at you. And it's destructive.

**Judi:** The blame. I can't get rid of the blame. And the **hatred**.. for that doctor. If there's anybody in this world I would like to **kill**, and be **allowed** to kill.. I would make that man go through so much torture.

But I'm to blame too. I failed as a mom. I think that's how I became a... a.. type A personality. I've always been told that I'm a perfectionist. I drive people crazy, I can't do enough perfect things, I can't do enough.. and other people drive me crazy. I think that's part of why I'm like that. I didn't do a good job then. I killed my son. And if I failed on the most important thing in my life... I'm going to fail other things, I can't let that happen. I think that's what's the drive.. I think that's what's doing it, why I second guess myself all the time. I can't let anything else slip, something else might go wrong. I can't make a mistake, somebody else will get hurt, something else will go wrong, I'll be to blame...

**Irene:** I'm sometimes a very **angry** person. I remember being so **angry**, and I think that was part of the grief too! Not being able to express grief must affect you in all **kinds** of ways! Not just in the physical and the psychological, in the breakdowns, but also I think spiritually, emotionally. An awful lot of anger is at yourself, too. Why did I let this happen, why did I let that happen? Over the years, I have been so angry at myself for letting these things happen to me. And realising, finally, that.. in an awful lot of ways, I had no choice. I didn't have the choice. I certainly know on an intellectual level, that with my daughter.. I gave her the best thing I could at that time, I did the best for her that I could at that time. And with that knowledge, I have to.. to let her go. And with my sons, I wasn't the best mother in the world. But I certainly was the only mother, the only parent they had. And I did my best.. at the time. And sometimes I didn't do my best at all. Sometimes I made.. dreadful mistakes. And did.. lots of things. But I can accept that now.

**Judi:** My whole life went to.. a **pot**.. when I was **7 years old. 41 years ago**. From **one** bad thing to **another bad thing**. And my son's right in the **middle** of it. And it seems to have.. **brought to life** more of what happened **before**.. and **reemphasizes** everything that happened since. So that he's like the focal point in my life. Everything I do.. has **him** in mind. Is this a good

decision? Am I making another mistake? It's always.. am I making another mistake, am I doing something right, am I doing something wrong? Second guessing myself all the time. Watching my body, so that.. **nothing**.. you know, I get a hang nail, it's like {mimicking panic} "oh my God! I got a hangnail!" Not that I'm neurotic, it's just that I'm just very keen.. with myself. Like, okay, this has happened, why is this happening, keep an eye on it.

Nothing positive has come out of my suffering. This was a **hell** of a life in the making. As far as I'm concerned, this is the **worst.. thing..** that could happen to **anybody**. I can't imagine **anything** happening.. like this. I mean, I've lost a **parent**. I've lost a **fiancé**. I've lost **friends**. But my own flesh and blood.. which **didn't get a chance**. I don't think it would have been so bad if he had had some small life, and he was ill, and they were trying to take care of it and all~ But he didn't have a chance in hell! It was the worst thing in my life. **Worst** thing in my life.

**Irene:** My unexpressed grief was very destructive in my life. That is not to say my life is.. wasted. Not at all. Because I lived, and.. through what I did, I'm a great survivor. I have friends who I can help because I'm an empathetic person, because of what I've lived through. You find **strength**, I think. And I think, had I not coped with the things that I **coped** with, in the way I did, bad or good, I don't think I would be the kind of person that I am. I think, what I'm trying to do, and I hope I'm achieving it, is letting you know there is a positive. That there is some positives in my life. And ah.. but it shouldn't take.. 38.... 30-some years, unfortunately...

I've experienced a lot of growth, hope, and peace over the past little while. And I've had to acknowledge that talking about Keirin was a necessary part of that. Telling my story, acknowledging him today, is maybe even an ending to the boxes.

**Judi:** I'm hoping this project might help me **face** some of the things about myself. This is the **first time.. in 26 years** I've had the opportunity to talk about this! I'm going to go home and have a real good cry. I **really** need a **real.. good.. cry**. I'll be home alone. I think I'll just sit down and cry. I haven't **cried.. cry** for a long time. I **prefer** to be alone. I'm very much a loner. I'm very much an independent person, on my own. Relying on myself a lot. Who else? Can't even rely on myself anymore. One of the reasons I wanted to get into this project with you was to see how **other** people were dealing with their grief. Am I the only one who **feels**.. some of the things that I'm feeling? I've never had the opportunity to tell anybody my story, and really everything that happened...

8

The fatigue is apparent in Judi's face as we prepare to wrap up for the night. She has unburdened a lot in a relatively short time, and with very little of the emotion bubbling inside of her making it's way to the surface. I've just finished mentioning to Judi a perinatal loss support group that has a newsletter service that helps bereaved parents make connections with others whose circumstances have been very similar. "Maybe you could meet somebody that way," I say, wanting to offer her some encouragement, some hope that there **are** people who can understand her experience and support her.

"You never know. You never know," she says. "I, like I'm hoping **this**.. will help me deal with it. You know, they say you can't live in your past. But you have to deal with your past in the present. And, that's.. part of my.. healthy progress now, I'm.. to the point, and I'm well enough that I can face this. I mean I haven't completely fallen apart tonight! And a few months ago I would have been in... you would have had to carry me out of here, I would have been just lost.



*But I'm doing pretty good today, I can handle it, I can see it logically. I know how I feel. And ah.. I'm just hoping I can just.. deal with it a little further, and.. and **really**... **settle with it**. Like.. make peace with myself on it."*

*"yeah-h.. I think that's the key is making peace with yourself and.. forgiving yourself."*

*"Yeah, forgiving myself for killing my baby."*

*"...Coming to accept that you **didn't** kill your baby."*

*"...Oh I don't think I--, see, how can these women put babies into cars and drive them into lakes? Or drown them in bathtubs? Like.. **how** can they **do** that?" Judi whispers her last words, sounding pained, bewildered. "It's--, it's so... inconceivable to me. And yet I know they have a mental illness too, and they need help."*

*"But yeah, with, with your history, it's hard to understand..."*

*"Yeah. So that's my little story." Judi laughs softly.*

*"mmmm.. I'm sorry."*

*"Well, it's... it happened. A lot of weird.. like a weird set of coincidences, and a weird set of circumstances **all** happening **together**. But... I'm dealing with it better, but.. I **would** like to forgive now."*

*"Forgive yourself, yeah.. yeah."*

*"..I don't know if I ever will, but.. maybe.."*

*§*

*March 2005 (e-mail)*

*Hello Myrna:*

*I read the first draft of my story tonight. Well, this has been one bad night of a lot of crying. I still keep things boxed up inside of me, they have nowhere else to go.*

*I don't have any changes to request or recommend...the facts are the facts....they don't change during time.*

*To follow up with you a little bit, I thought you might like to see a bit of my personal history update:*

*TODAY:*

*Three years later, and things are still very much the same. But, both my husband and myself did graduate from the university this past spring....some growth!!! I am also a two time award winner for floral designing.*

*I am still my mother's caregiver, and it has been made worse since she has developed dementia.*

*My husband and I were seeing a marriage councillor up to 10 months ago, but my husband's decision has been to stop going. I don't really care, it wasn't working anyway, because he didn't want it to work. So we are still married, living together, celibate, as only friends.*

*I have reached the grand old age of 50, and I am presently going through menopause... the final nail on my child bearing coffin!*

*Forgiveness....NEVER!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!*

*Acceptance.....NEVER!!!!!!!!!!!!!!!!!!!!!!!!!!!!*

*Contentment and Happiness.....NEVER!!!!!!!!!!!!!!!!!!!!!!!!!!!!*

*And by the way, the black panther of death is still following me around! A special friend I've had in my life since I was 19, is dying from prostate cancer.....again, more grief to bear.*

*My psychiatrist retired and left my mental health care up to the marriage councillor, who then turned it back over to my G.P. So, NO, I do not have any mental health assistance, only the 80mg of Prozac a day to keep me somewhat under control. I have also developed a heart condition, that they are still trying to bring back into a normal level. My doctor now also has me on morphine, to control the pain from kidney disease, and from my messed up skeleton's problems..... more drugs!!!!!!!!!!!!!!!!!!!!!!!!!!!! Doctors don't seem to understand stress kills!!!!*

*Thanks  
"Judi"*

*You have my complete support in going ahead with this section of your project.*

*I look forward to seeing you again.*

*§*

*I steer my car over the soft, thick, dirty snow at the side of the street and slow to a near-stop as I peer at the numbers on the houses on the right. I spot Judi's house and pull into the driveway behind her vehicle. I'm not sure what to expect from our meeting today, but after talking to her the night she sent the e-mail, I felt strongly that I must meet with her face to face again. I just hope that returning her story to her now, 3 years later, hasn't only served to cause her more pain.*

*Judi says hello to me from the front step as she picks up the mail, and I feel my way carefully over a small patch of ice, formed from the melting snow yesterday. Her hair is much longer now and maybe a bit greyer than when I saw her last. She leads me into the house and quickly introduces me to her husband as I'm taking off my shoes and coat. She asks if I'd like to meet her mother, and we make a brief stop in the living room to say hello before retreating to the basement for privacy.*

*Two half-grown kittens come and go in the sitting room as we talk for the next hour. Judi strokes and plays with them as she talks. She speaks softly, matter-of-factly, calmly but with an*



*undercurrent of deep sorrow and emotional fatigue. My heart breaks for her as she repeats much of what she said in the e-mail: that things have not changed for her in the past 3 years, with the self-blame, anger, and hopelessness for her future essentially the same as ever. She tells me that she lives day to day, only surviving really, and she makes no long-range plans and doesn't allow herself to dream (or care to dream) because she feels she just gets shot down if she does. I ask about suicidal thoughts, and she says, no, she's given up on that. ("I'm not good at that either.") She has "resigned" herself to the way she feels and the way her life is, because she sees no way of changing any of it – the self-blame is permanent in her view, and there is no prospect of self-forgiveness. She remains productive, involved heavily in volunteering until recently, taking care of her mother, and her floral design interests. But the underlying feelings of discontent and hopelessness for her future will not leave her. She now has no mental health support aside from continuing to be on a high dose of Prozac, under her family physician's care. She is now on permanent disability because of the bipolar and fibromyalgia, which she is grateful for so that she no longer has to convince her insurance company of her inability to work. She is having health concerns, which she attributes to stress. She has a number of stressors in her life in addition to the ever-present grief and self-blame, including her mother having a recurrence of cancer and requiring further surgery, a friend dying of cancer, and the issues in her marriage. Her hopes of ever having a family, long since dead, have symbolically been put to rest by the onset of menopause.*

*As we talk, I don't try to talk Judi out of her self-blame, as much as I still feel compelled to. I make some faltering attempts to help her see a different way of interpreting things, such as her belief that God is punishing/testing her. She's a part of the Church of England, and although she does not attend church she speaks of a definite relationship with God. But it does not sound like she draws much comfort from this relationship, only further self-blame and the idea that things might improve for her when God wills it.*

*I try to convince Judi to arrange to see a psychologist specializing in grief counselling, for one session at least, just to see if it might be helpful for her. I ask her to allow someone to support **her** emotionally for a change, to not "write herself off" in terms of finding peace. If nothing else, I say, counselling could help her deal with the stress that is contributing to her health problems. She considers my suggestion, not refusing but saying she will discuss it with her husband. We talk about complete understanding of her grief by another person being impossible, but that there are people who can be supportive and compassionate, who "get it".*

*Judi admits to being jealous of me having another baby, but says that she's also happy for me. I tell her I clearly remember feeling the same way when we were still uncertain about our*

*ability to have more children, and that I sometimes found it hard to be happy for friends and acquaintances who announced they were pregnant. For Judi, never having the chance to be a mother to a living child of her own is one of the key aspects of her experience that she sees as preventing her from achieving self-forgiveness, acceptance, or peace within her ongoing grief.*

*Judi says that her husband has read most of her story now. She said to him, "Do you want to know what your wife is really all about?" when she asked if he wanted to read it. He cried and has been quite upset about it, because this is the first time he has heard everything in depth. She hopes this will spur him to seek out counselling again, and that perhaps they can make in-roads with their marriage issues at least.*

*As we wrap up our conversation, Judi mentions that she continues to hear of healthcare horror stories that make her very angry, given her experience. She says she hopes my work can help others, and maybe make a difference within the healthcare system. I leave Judi's house feeling deep sorrow, but also a glimmer of hope after our hour long conversation. If only she will go for counselling, talk more about this issue and not just her bipolar and health concerns... allow her grief to be heard by a compassionate listener, to see the light of day...*

## 8. STACIE & DAN

*My eyes feel gritty as I stare at the computer screen, scanning through Dan and Stacie's transcript of our interview before sending it off to them. In their early-twenties when their daughter from a set of twins died 6 ½ years ago, they are now in their late 20s/early 30s. Thinking about them now, I realize that I related to them in a different way than most of the other participants I interviewed, perhaps because they were closest in age to me. Reading on, I come to the part of the transcript in which they talked about their relationship problems following Reanne's death. The dryness of my eyes is suddenly no longer a problem as I well up with tears of affection for this wonderful couple. I turn away from the computer and reach for my journal, wanting to preserve my thoughts.*

*"I love these people," I write. "They are so laid back, wise, full of common sense.. just lovely, lovely people. They inspire me. They click so well together, even as they talked to me, interrupting each other yet working together to tell their story. It seems to me they are together now for life, bonded in a way that many couples never know. It shows how central the experience of losing their daughter was to their lives, what an impact her death had on them. Her death triggered their problems and separation. But it also brought them back together, because no one else could ever understand what they had gone through except each other. It was inevitable that they would get back together – maybe because of their relationship history before their daughter died, but maybe too, because of the bond that they shared because of her death. It's sad and it's beautiful and it's profound – and it's a tribute to their beautiful baby girl that they love so much." (Journal entry, March 2002)*

§

*Scene: It is late February 2002. Dan and Stacie's living room. Myrna sits on the couch with her back to the window overlooking the street. The door to the kitchen is located on the right side of the wall across the room, and an entertainment centre with a T.V. and stereo stretches from the door to the side wall on the left. In the far corner of the wall to the right is a door into the hallway. Dan and Stacie sit on a love seat to Myrna's right. A coffee table sits in front of the couch. Magazines, a T.V. remote, and some photo envelopes are lying on the coffee table. A large display shelf is to the left, containing photos of Dan and Stacie's sons and mementos of Reanne.*

*Myrna finishes setting up the recording equipment as Stacie tells her about their two sons, who are on spring break and visiting their grandparents. Dan leaves the room for a minute*

*and returns with 3 drinks and places them on the coffee table and end table next to Stacie.*

*Myrna launches into an explanation of her reasons for doing the project, and then turns it over to Dan and Stacie to begin telling their story.*

Myrna: I'll let you just go ahead, and.. whoever wants to start, or you can both tell, or whatever works for you guys.

Dan: *(looking at Stacie)* Well, you were out of it for most of it.

Stacie: *(looks at Dan with a slight smile, and nods)* Yeah.

Dan: So.. ah.. it was ah....

Stacie: I was 26 weeks pregnant

Dan: Yeah.

Stacie: They were very premature, both of them. Very premature.

Dan: Yeah. They ah.. brought her into the hospital, they phoned me at work. I raced down, and she was in premature labour, and they tried to stop it. They did everything... *apparently*, they possibly could. Ah.. *nothing* worked. So finally.. *(takes a deep breath)*

Stacie: Three days after..

Dan: Three days after, they decided to do a Caesarean. And ah.. so they raced her into the operating room, and I came down and... basically, her water broke. And the little.. girl was-

Stacie: *(Interrupts)* Well, like the three days previous, when I went in to my family doctor, and I said, "I don't feel right, I'm cramping." There was actually.. fetal parts, like the mucus plug had fallen out, and there was actually a leg in the birth canal. *(Myrna makes a noise of dismay.)* So for the three days, she had been in.. distress labour, in the birth canal.

Myrna: And they didn't know that? Or they~?

Stacie: They knew it, but there was nothing they could do. Because the water had already broken, and they were just trying to maintain the fluid. They had me on *constant* ultrasound, making sure the fluid level was still okay. And trying to prolong the labour. Keep her in as long as possible.. *(laughs softly)* is.. the biggest thing they tried to do.

Dan: Yeah. And then... well, like I said, they brought her in. Finally decided to do the Caesarean. And.. she *(motions toward Stacie)* had, I don't know, an allergic reaction to the anaesthetics. They had got the babies out. I saw them, eh.... my little babies.. they were so tiny. And they put them on their little carts, and they raced them away. And.. I was worried about her. *(gestures toward Stacie)* And all of a sudden everybody said "Get out of here, get out of here!" And.. her lungs collapsed..

Myrna: Reanne's~?.. or yours!? *(shifts her eyes quickly from Dan to Stacie)*

Dan: No, hers! (*speaking at the same time as Myrna*) Stacie's, yeah. She had it.. after the reaction to the anaesthetics or whatever, eh. So they.... *raced* my babies out and then... here's poor Stacie..

Stacie: (*laughs*) Race them up to NICU, and me down to ICU.

Dan: So I go out in the hallway, I was all... I was freaked right out, you know, I don't know what's going on, everything went haywire all of a sudden, eh. And ah... I went upstairs.. and my babies were in NICU. And of course they were trying to stabilize Stacie and everything. And I went and I got (*sighs*)... to go inside to NICU.. and I got to... touch my little girl. One, one touch while she was alive, eh. And they had some kind of emergency in the NICU, and they kicked me out. And by the time--, I never got back in, and my~.. you know. So I went downstairs to see Stacie. And she's laying there with a tube down her throat. And it was a very stressful, very ah.. emotional day, everybody was really... just wound right up. And our oldest boy, our other boy, he was 3. He hadn't been home for *days*. So finally, they got Stacie all stabilized and everything. I went home, I got my other boy home, and we're... going to sit down. I'm phoning everybody, (*imitates a stressed/upset voice*) you know, I'm on the phone on the phone on the phone. And finally, I got off the phone and Stacie's mom called. And the doctor was trying to get a hold of me. So I phoned the hospital. And over the phone he said, "Your daughter's dead." (*Said in a mimicking voice, sounds harsh, abrupt. Myrna makes a noise of disbelief and disgust.*) I'm like.. "What?!!!" you know?! And ah... you know, well, he wasn't *quite* that blunt I guess, but he says, "I have some bad news." But it shouldn't have been done over the phone,

Myrna: over the phone!

Dan: as far as I'm concerned.

Myrna: exactly!

Dan: He should have said, "Please come down to the hospital," and.. you know, "We need to talk," or whatever, eh. And ah... so the doctor said, "We have to tell your wife."... Well.. (*Myrna 'laughs' in a shocked/disgusted way.*) she's laying..

Stacie: I'm already dying, don't~

Dan: ..she's laying in the ICU, *stoned* out of her mind with a tube stuck down her throat, she doesn't even know what her own name is, right. I said "WAIT!" I said, "I just have to get somebody to watch my son," I said, "I'll be there in like 25 minutes." (*mimics doctor*) "Well I don't know if we can wait that long," ... you know

Myrna: *Why?!!* Oh, my God.

Dan: I don't know. Just by chance her sister-in-law showed up, and I raced out of the house.

*Roared* down to the hospital... They had already gone and *told* Stacie that our daughter was dead.

Myrna: (*makes a noise of disgust*) Oh-h, God!

Dan: Okay? And I was *flipping out*. I was ready--, I was going to go up there, and I was going to tune this doctor in, eh? So.. they did this, and I couldn't believe it. She was in ICU, in *distress*, you know, like they're trying to save *her* life. And then they go down there, like, I don't understand what the *hurry* was?! Why couldn't they wait ½ an hour? (*Myrna voices her agreement*) You know? And.. I, I still don't get it, and I'm still *very, very* upset over it. You know, and I don't-

Stacie: (*Interrupts*) And then that set me back, because I went into..

Myrna: Well, yeah!!

Stacie: I went into cardiac arrest the minute they told me.

Myrna: Yeah! Like that makes.. no sense!

Dan: And I'm very.. I'm STILL *severely* angry over why.. you know, like... what, *what* was the hurry?? She's.. she's *gone*. Let's just take this.. one step at a time. Why did they have to dump it all on her~, (*slaps his hands together*) like BANG! You know?

Myrna: Yeah! Yeah. Like, medically, wouldn't they *know* that would be bad for her recovery? (*Said sarcastically, with an incredulous laugh.*)

Dan: Obviously they.. don't know what they're doing! They.. they... treat it like... I don't know if I was just supposed to act like it was just a.. stray dog on the street?! Or~.. you know? Like this was my *daughter*. I know she only lived for 8 hours. You know. But she was *there*, she was *real*, I *touched* her. You know, and it's... She was.. she was.. *there*! You know. And I... and I still feel guilty for the fact that I got to... at least touch her once while she was alive...

Myrna: You feel guilty that you did, and~

Dan: Yeah, because Stacie didn't. And I got to see her. Stacie never even *saw* her. They had the big curtain up-

Stacie: (*Interrupts*) I.. actually.. voided out of it. (*Dan sighs sadly.*) Because they said, "Do you want to see the babies?" Right after they were taken out. And I thought, "They're little, they're in distress, just get them to NICU. I've got.. *years* to be with them." So I said, "Just take them." So..

Dan: Yeah. So she didn't even-

Stacie: (*Interrupts*) And by the time I got to see her she was already passed away.

Myrna: Yeah-h. You did see her afterwards at least?

Stacie: Yeah, they brought her down to ICU.

Myrna: Was the timing of that bad too, or were you glad they did that, or~?

Stacie: No, actually, when they brought her down... that was after, like most of the family was already there. They did wait for that. They just told me... (*The phone rings. Dan quickly removes the microphone from his shirt and places it on Stacie's. He jumps up to answer the phone. Stacie and Myrna glance toward Dan, but keep talking.*) They just told me when nobody was there. Which I can't understand, because there'd been nothing but family support for 4 days in the hospital. So.. you'd think they'd get the hint that there was always a family member there for support. But...

Myrna: Wow.. that's.. unbelievable...

Stacie: And that, I kind of.. couldn't figure out why they did it that way. And it's true, I mean I was... you know, when you're in ICU, and you're on life support, there's no way, I mean.. I don't even remember being there. (*soft laughter*) I don't even remember being there, let alone what was going on, and..

Myrna: yeah, yeah...wow..

Stacie: So... and the preparation too, like that's one thing I'll admit, they do prepare you. They had told me that with children that are premature, there's a 50% survival rate. So they had pretty much let me know the minute I went into labour that.. I was only leaving with one. You know, best chance is one...

Myrna: Still.. I mean, that doesn't sink in.. you know, and~

Stacie: No, it doesn't. 'Cause you think, "Well no! It's not going to happen to *me*. My life is perfect." (*laughs*) And also, statistically, at that gestation little girls generally do better.. than little boys. And also, I got the weights confused. I thought Reanne was heavier than Aaron. So when they came downstairs and told me, they're telling me the heavier.. healthier.. *girl* passed away, when everything else is telling me the *boy's* the one that's not supposed to survive. (*laughs softly*) So.. at that time, I thought that I'd lost both of them.

Myrna: mmmm, yeah.. wow

Stacie: you know. There was no doubt in my mind that.. he wasn't going to survive either.  
(*laughs softly*)

Myrna: yeah, yeah.. wow..

Stacie: (*Pauses briefly to listen to Dan on the phone in the kitchen*) He's still on the phone.. it must be the boys calling from Grandma's.

Myrna: (*glances toward the doorway*) Oh yeah.. So how is.. Aaron?

Stacie: He's perfect. (*laughs softly*) He's tiny. He is still very little for his age.



Myrna: Yeah.. he didn't have any health problems or any~?

Stacie: No. No, amazing. Like he had.. when he was 3 weeks old they did heart surgery... to clamp his heart. And at 8 months old they had to do double hernia surgery, 'cause he was on a ventilator, he was in NICU for 3 months. So, because of the ventilator, most little boys do get hernias. But since then, he's been fine. (*Stacie and Myrna look up as Dan returns. He settles back down on the loveseat and mentions that the boys went to see Peter Pan.*)

Dan: What were you guys saying while I was gone?

Myrna: I just asked about Aaron, and how he was, you know, like his health and everything.

Dan: Yeah, that was-

Stacie: (*interrupts*) His health is excellent now.

Dan: Ah.. it was.. it was tough going. *Holy smokes*. And.. it was terrible that winter, every time something happened we had a big snow storm (*Stacie laughs and Myrna exclaims "oh no!"*) It was terrible. Um.... It was tough watching that little guy... you know, every day. Going to visit.

Myrna: Yeah-h. And for 3 months, you were saying?

Dan: Yeah. November 9th 'till February.. 11th I think it was. Yeah.

Myrna: Wow, yeah. What was that like, being in that ward, where you were so angry at these people, right, and~?

Stacie: That was the whole family's biggest thing. We all kind of had a blowing out one night after I got home from the hospital, because.. like I was 2 weeks behind everybody! I mean, I had just barely gotten awoken from being in ICU, drugged for 2 weeks, so I was kind of behind everybody. So when I finally got home, it hit me. You know, like everybody's talking, and they're almost in this stage that.. I wasn't.

Myrna: You weren't there yet, yeah..

Stacie: You know, I was still angry, I was still.. (*laughs*) in that initial first shock. And I freaked. I screamed at Dan, and I screamed at my mom and my dad. Because, you know, here I am, I'm the one with.. you know, *engorged boobs*, and a Caesarean going from hip to hip, and I don't even have *one* child. You know, like I went into the hospital *over-pregnant*. And I came home with *nothing*. And that's the night I broke. And it was kind of.. everybody was on the same wave length, like.. well, you want to blow-up that hospital, you want to go~ But we couldn't, 'cause Aaron was there. You know, like that-

Dan: (*interrupts*) Everybody had to.. had to *back up*.. quite a ways-

Stacie: (*overlapping with Dan*) like all of your anger-

Dan: and start over again, eh, and it was~

Stacie: Like that's one thing that I will say.. helped a lot. Like having Aaron.. was a help.

Because as you'd be cursing the doctor, (*laughs*) like.. I know it wasn't his fault, but you have to blame somebody. So as you'd be upset and.. blaming him, then you'd think back, well, Aaron's still alive. And you didn't want to go tell the doctor off because, well, then he'd make sure Aaron didn't live..

Myrna: oh-h, man

Stacie: you know, like.. you always had this-

Dan: (*interrupts*) Your brain just goes.. squirrely on you.

Myrna: yeah, yeah. Things don't get all that logical or whatever

Stacie: yeah, it does-

Dan: (*interrupts*) We had to.. *back up*... And it was.. well I remember (*sighs*)... it was.. . a couple days, or 3 days after she had passed away. Stacie was still in ICU, of course. And her parents and my parents and my brother, and my best friend of 20 years – God bless him – him and his wife came down. And they brought our daughter down.. and we could all.. you know, say our last little thing. And when they came and told me that they were taking her away, I... just about snapped. And you know, it was ah... it was really rough. But I'm happy they did that for us, you know, like I, I got to hold her, and.. and ah... They did the same for Stacie, but she doesn't remember it, I don't think, quite as well as.. she should have. But there wasn't really anything... like I couldn't expect them to hold on to her for 2 weeks, waiting for Stacie to get better, you know. And ah.... I don't know, it was.. when they came to get her back I wouldn't let her go. (*laughs softly*) And it.. it was really rough, you know.

Myrna: Yeah-h. How long were you.. with her? Holding her, and~

Dan: (*sighs*) They... well, everybody kind of took a little shot, you know, like my parents and her parents came in the room with me, and we sat there for awhile. And.. you know, we just... held her. And ah... then, I think I sat.. well, time didn't mean much to me, at that point, it could have been 5 minutes, it could have been an hour, I'm not sure. But it was quite a long time, I think, I sat with her by myself, and.... (*sighs*) told her my hopes and dreams.. that were never to come, and~ (*Dan lets out a breathy sigh and is silent for several moments, swallowing back his emotion.*) My little girl. (*Said quietly, his voice thick with emotion*)

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Stacie: And that was the hard part, the little girl. It took everyone a long time to admit that one. 'Cause we already had a boy. So it was working out perfect so far, have one little boy... And pregnancy for me, like even my first one wasn't that good. I just don't do pregnancies well. So when I got pregnant the second time, even my doctor was quite upset that I was

pregnant again. And they told me 2, we were having twins. So, I can do one pregnancy and get the 2 babies out of it. Have my three kids, my 2 boys and a girl. I didn't know for sure, no tests had ever proved it, but.. I had told everyone the whole time I was pregnant, boy and girl, boy and girl. So that was a hard hit. Like everybody you talked to afterwards, like months afterwards, when people's feelings would actually come out, they'd all say the same thing, you know, all we could think was, "Why the girl?" You know, like *now* we wouldn't trade Aaron for *anything*. But at the time, it was a real hard... "Why her?" you know.

Dan: Yeah. That was really hard. I had a lot of support. Where I worked was fantastic. They gave me time off, they did *everything* they could for me. And everybody was really fantastic, they all sent flowers and~ you know. But it was.... I had all the support that a guy could ask for I guess, but still, it was my wife and my child in the hospital. And no matter what anybody could do for me, it seemed like my whole life was upside-down. And, then I had the hospital phone, this one really upset me too... I had a hard day, the day the babies were born. You know, with Stacie and everything happened, and I just didn't know how to handle it anymore. And when they brought Stacie down to intensive care, I eventually went home, and I *hadn't* gone downstairs to visit her before I left. And the hospital phoned and asked me why I was *angry* with Stacie. Because I didn't go down and visit. And I told them, I'm not angry, I had so much going on. I said, "She wouldn't have known if I was standing there, or sitting on her chest," you know. I thought I would just let *her* get calmed down, and everything under control, and.. you know, I was thinking of *her*, not *myself*. And I'd had such a day, with everything else. And this was before I found out what happened to Reanne, before I knew that she had passed away. And I wanted to get home and get my other little guy, you know, *his* life was turned upside-down, and he knew it. He didn't know what was going on. "Why isn't Mom here, why am I stuck here for this many days?" So I wanted to get him home, and give *him* something.. back to normalcy. And then the whole thing got turned upside-down again, a few hours later. And it was... it was pure hell... That's probably the *wors-st day*.. I will ever have in my entire life. You know, I can't think of anything that's going to be worse. Unless of course.. something was to happen to one of my boys, now.

Stacie: The nurses in the NICU were really good, for the most part. Everyday they would write little notes from Aaron. And they would take Polaroids and they'd send them down to me. We still have some of the things. Aaron had the little Raggedy Andy on his name tag on his incubator. And Reanne didn't have one yet, 'cause she was only 8 hours old. But they made Reanne's little Raggedy Ann so I could have the pair. The nurses gave us all the stuff she touched, her little blankie, her little booties that were about four sizes too big. And they gave me

her card, and her little leg bands, and her foot prints. And a picture of her wearing everything in the package, so I'd know she wore it all. All of that was ready for me when I went home. So that was good, good to have all of that. Because like they said, in a case like that, you have nothing. With how premature they were, we hadn't even really started anything at home yet.

Dan: I think it's even *more* of a tragedy losing a baby than an older child... because, at least if their child was 7 or 8 or 9 years old, they have some memories. Like this way, you don't have *any* memories. You have *nothing*. All you have for memories is, I've got that initial, "I'm the happiest man in the world, I've got a little boy and a little girl!" And you're on the *biggest high* in the world. And then 8 hours later, you come *crashing* down to earth. And all you've got is that brief little moment of joy. And then you've got what's going to go with you for the rest of your life, of... she's not here, I'll never have a memory with her, I'll never.. you know, buy her a dress, I'll never see her in pigtails, I'll never.. see her graduate, get married. And, like I say, if you've got memories, I think it's *better*. But I can't really say that honestly either, because that hasn't happened to me. But, like if you have 7 years of joy, and fun, or however many years.. you've got pictures, you've got birthdays, you've got Christmas. You've got all these things. And.. what do I have?

Stacie: I've tried to picture what she would actually look like. Because of what she looked like then, I mean, she was a baby, she looked like every other baby, but premature, you know. So we don't even know if her hair would have been blond like her big brother's, or would it have been dark like Aaron's, would have Aaron been.. close in looks because they were twins? You know, we pick out little things, like she had really long fingers. Really long. So it's like, "Oh, that's definitely my hand." And both the boys have Dan's family pug nose, and hers is really straight. You know, so I think, "Oh, she would have looked just like me." Which.. neither of my boys look like me, they're both the spitting image of Dan. And that's the thing, you're never going to know what she would look like. You have to try to picture her... a little more grown up.

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*"Yeah, a lifetime of wondering, and.. imagining... yeah... What's it.. like for you, not being able to... have more contact with her and.. you know, being drugged up when you did see her, and~?" I ask. I'm moved by Dan's feelings of guilt over Stacie not having any time with Reanne, something he had no control over but regrets anyway. I'm reminded of my own feelings of guilt over not thinking to tell the nurses we wanted more time with Jacob. I think it's beautiful that Dan and Stacie's family and friends were able to share in their time with Reanne. Why didn't we think of doing that? Ross' parents never got to see Jacob. Why did I let the nurses take him away after only 20 minutes?*

Stacie shifts to a more comfortable position on the loveseat, but continues without pausing. "The funny thing with mine was um... I think when I left the hospital, I actually left with survivor's guilt. You know? Like I had this thing in my head that God was so busy trying to save me that day... that He didn't have time for both of us. You know, it's weird but that's.. you know, you do the math, and you're like, well, population-wise, if He can only save so many girls a day.. well, He saved **me** instead of **her**. You know, I kind of left... with that feeling. Almost a.... you know, and that's another thing. Like, what did I do wrong in the pregnancy? What could I have changed? How come I couldn't carry them to term? You know, a lot of.. hurt, that way. And a lot of disappointment that way. Like, well, people must just be disappointed in me, I can't even bear children, you know." Stacie laughs, a comfortable laugh of one who is at peace with thoughts and feelings that she's been able to come to terms with. "It was.. pretty hard that way, too. And I think--, I got really sick of people saying, 'Well, it was probably for the best.'"

I snort in disgust. "Don't you hate that one?" It's a platitude I've come across too often, including in my own experience.

"Why is it probably for the best?" Stacie says sarcastically. We all laugh, united in our ability to see the absurdity of such comments that have hurt all of us in the past.

"I never agreed with that. You know." Dan says.

"Yeah.. there's always that one." I think back to comments I heard in the first few days after Jacob died, well intentioned but so completely oblivious to the implications attached. If it was for the best, does it mean his life wouldn't have been worthwhile if he had survived??

The room is buzzing with our anger as we recall the infuriating comments we've heard. Stacie spits out passionately, "And um.. oh, 'Well, something might have been wrong with the child.' Well~"

We're on a roll now. The memories of platitudes heard and filed away come to the surface quickly. I say, "Yeah. 'She's better off, she would have suffered' blah blah blah." I laugh at my own passionate outburst.

Stacie smiles and continues, thinking of Reanne's seemingly perfect body. "It's one of those.. okay, there's no proof anything was wrong. But even if she had spina bifida, I would rather have a child with spina bifida! I would rather have a child with Down Syndrome! You know, you'd have your **child**. More care, yes. More time.. it would be a.. much bigger responsibility. But you know, 'Oh, well God chose to give you the easy route, and he just took that little angel right up with~' **Don't** tell me that! You know," she says with a laugh.

"Yeah! It never makes sense to me that people think that about babies, but then if you're talking about a 3-year-old, they'd say, 'Well, why would you say such a thing?!' You know.."

Talking with other parents who've lost a baby allows my anger and frustration to come out full force, rather than suppressing it as I might with someone who hasn't 'been there'. Stacie and Dan agree, and I barrel on with my rant. "Like I don't think people.. like, they don't get it, this is a **child**. You know, this is **your child**."

"This is~ That's exactly it," Stacie nods as she voices her agreement.

"Yeah, yeah, you're right," Dan says, more subdued than Stacie and me. "I would have rather have been able to **find out**... than to just have her taken away so suddenly. You know. Um.. I would have **liked** to have known, I can't..." His voice trails off, the uncertainty clear in his voice, the wondering that will last a lifetime.

Stacie shakes her head, knowing what Dan's thinking. "Well, there was nothing wrong. I've read her reports. There was nothing wrong. There was nothing wrong with **Aaron** either.."

"Did they do an autopsy, or~?" I ask hesitantly, knowing that many parents have strong feelings against autopsies.

"I wouldn't let them," Dan says quickly, firmly.

"No. He wouldn't let them," Stacie repeats.

Dan continues. "I wouldn't let them. I told them if they touched her, I'd come down there and I'd slice **them** up." He laughs softly at the memory of his outrage at the suggestion. "And that's what I told them, I said, 'you cut her,' I said, 'I'm going to cut your head off.' You know, I said, 'She came into this world and she looks **perfect**, she's **beautiful**, she's the prettiest thing.' I said, 'You are **not** cutting her up.' I said, '**No way**. You leave her alone. She came into the world looking perfect, she's going out the same way.' you know, and ah.."

Stacie takes up the train of thought. "Yeah. And he knew my views on.. you know.. autopsy. I mean, okay, if there's a reason, yes. I didn't really see it as a reason, I saw it more as probably one of.. their biology classes." She laughs softly. "You know, that's.. how I would view that. Why do you need a biopsy on a 26 week gestation baby? That in itself tells you why the baby died." She laughs again, sarcastically.

"Yeah, not rocket science here, eh," I say, fully in agreement with them. I find myself wishing we could have avoided an autopsy too. I don't allow my thoughts to go any further, the visual image too horrifying to think of.

"Yeah, like," Dan makes a sucking noise as he brings his hands together, "lungs collapsed, they stuck together. Why? She had no surfactant. You know, like it's simple! It's, you know, I have a grade 11 education, I get it!" he says sarcastically. We all laugh.

Stacie nods in agreement. "Yeah. And because it was a collapsed lung, you don't need an autopsy. There's no reason to have one."



*"Yeah, you don't need to be a doctor to know that," I say.*

*"Exactly." Stacie nods and reaches for her drink on the end table.*

*Dan's anger is obvious on this issue as his thoughts continue to roll out. "You know, if ah.. if your puppy dies on the farm, you don't go and cut him up right away. You know, like, well he was.. he was only this big." He brings his hands inches apart. "Premature. You know. It doesn't take a rocket scientist to figure this one out, you know."*

*"Yeah, a little.. a little common sense," I say.*

*"Yeah, it boils down to common sense, and.. I, that's the way I felt too, is like, well, you're going to have a bunch of ah.. medical students~ This is not a frog in a science lab. You know, this is-" Dan's voice is calm, but his outrage is clear.*

*Stacie interrupts him, her thoughts moving in a new direction. "And I know there are people who donate.. things for these purposes. 'Cause they do need them, to learn and whatever. But not me, I'm too selfish. Like.. that's me. And it's one of those things of... you know, everyone's like, 'Well did they even ask if they could take the organs and maybe give them to some other child?' It's like, 'No, they didn't.'"*

*"For her it was like this big!" Dan says, holding his fingers close together. "What are they going to do with it, you know."*

*Stacie nods. "Exactly. Because they were so premature, that wouldn't have been an issue. But even had it been.. you know, like you watch these news reports, where that one woman carried her baby to term knowing it was dead already.. just to donate everything. Like that takes.. **one hell of a woman**. I'll give her that, you know. That's **great** for her. But not me. It sounds mean, but I knew myself, I'm selfish enough.. I don't even know if it's selfish.."*

*I interrupt, saying "No, just.. your preferences, or your~"*

*Stacie continues, "..my preferences.. no one's getting joy out of my sorrow." She laughs softly. "Like it sounds bad at the time. You know, like.. little things I can do. Fine. You know, if.. telling some mother my story helps her, great."*

*"Yeah, you can help people in other ways, whatever way you feel comfortable with," I say, trying to let Stacie know that there's no reason to feel badly about this.*

*"Exactly. Exactly," she says.*

*I pause for a second and then say what's been on my mind as we've talked about the autopsy. It feels like I'd be deceiving them if I agree with everything they say without letting them know what my own experience was. "I know my husband felt strongly about the whole research thing. It was kind of something his grandfather had done, donated his body for research, and~.. um.. You know, our son Jacob had ah.. so many birth defects, and they weren't going to be able*



*to tell us exactly what it was. And so we said, okay, we're doing an autopsy, 'cause we want to know, so that we can plan for future children too, and.. you know, to have some answers, you know. But it's a different-*"

*Dan cuts in, saying, "yeah that, you know, in that case.."*

*I continue, nodding, "-totally different situation. Yeah. I think in your case I wouldn't have.. done that either."*

*Dan agrees. "No, she was ah.. like I say, she was perfect, she was beautiful, you know..."*

§2

Stacie: She died of collapsed lungs. I actually saw all the reports from Reanne, and she was fine. Everything came back normal. Small. A lot of it came back small, but it all came back normal. And it bugs me, because she spontaneously cried at birth. And for 26 weeks, that proves *good* lung power. Whereas Aaron had to be resuscitated when he got up to neonatal. So, it only *proves* that she *was* the stronger~.. And the only thing – my old doctor had actually sent it to the College of Physicians and Surgeons to examine – is that she was never given surfactant, a medication that helps premature babies with their lungs, since they're not fully developed. So, the chances are her lungs could have been stabilized. Like, I had pneumonia. And that's why they finally had to do the Caesarean, because I was going downhill. They had to get the babies out, stabilize me. That was the only choice. And she had pneumonia too. So they had started her on really high antibiotics. They chose to try to cure the pneumonia before they tried stabilizing the lungs. Aaron was fine, he went right on surfactant. But the reports said that her lungs collapsed once, and they were able to reflate them. And then they collapsed a second time. And without the surfactant, they couldn't do it. And even my family doctor at the time agreed that, *why* would you be trying to battle pneumonia if you don't even know the child's stable? Like they should have stabilized her *first*. But unfortunately, like I've seen the letters, and the College of Physicians pretty much wrote back to the doctor that at that age of gestation, there's no law case. With 26 weeks gestation, they could find *no* neonatal specialist that would go on *my* benefit, and say, "Oh, well, the chances of survival are *great* at that~" And it's true... that with or without surfactant, with or without pneumonia, 26 weeks gestation is too early to determine that the child would be fine and would live. But I think everybody found it hard... like it's hard to look at Aaron and imagine what was so wrong with Reanne? You know. It *is*, it's very hard.

Dan: Another thing that kind of got me when they rushed the kids in after they were born – you know, it was pretty stressful, everything was happening all at once, and then the nurses

came along and they said, “Oh, well we’re doing a...” some kind of a test run on surfactant, synthetic or from a calf. Like from a cow, okay? And they said, “Do you want your children to do this,” or do you just want this or that, or whatever, and I didn’t know what the heck’s going on, so I just said, “Well, sign them up, do whatever, I don’t care, just take care of them!! Why are you guys sitting here wasting my time!” And I said, “Which one are they going to get?” “Well we’re not going to tell you. They’re going to get either one, we don’t~” You know, and it’s like, “Well.. why are you wasting my time?” I’m *freaked out*, I’m ready to *punch* somebody. You know, just to get the *aggression* out, because I’m just.. *stressed*. And you guys come along with these *dumb* questions. And it’s like, “Just give them something so that they’re okay!” That’s all I cared about! You know. I said, “Look, I’ve got my 2 children up here, I’ve got *another one* that’s been.. not home for a week. My *wife’s* in *intensive care*!” You know, because they *doped* her up too much. “Why are you asking me dumb questions?! Get it together, *save my kids, save my wife*.” You know. “Somebody give me a shot in the butt and calm me down..” I was just about to that point where I was going to have to be sedated. Dad thought they were going to have to sedate me. He said, “Either that, or I’m going to hit you with a frying pan.” ‘Cause I was just *wired*. I couldn’t sleep, and.. oh-h-h, man.

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*Looking through Dan and Stacie’s transcript, I notice my own reactions, during the interview, to their stories of things that angered them about their experiences with hospital staff. I didn’t make any attempt to hold back my shock, anger, bitterness, and sarcasm. Although I never expected that I could hold my emotions in check or be unbiased during the interviews, I do recognize that some things brought out more of my anger than others. The issue of difficulties with the health care system was one of these areas. Sorting through the list of parents I’ve interview, I realise that all but one or two mentioned at least minor problems with or insensitive treatment by health care staff at the time of their baby’s death. Some, like Stacie and Dan, had more serious concerns about things that were or were not done that could have contributed to their baby’s death. I’m struck suddenly by memories that I tucked away and haven’t thought about in a long time. I guess I’m one of them too. I generally had no concerns about the treatment I received by the doctors and nurses before and after Jacob’s birth, and even felt that most staff involved were extremely compassionate. But there were problems which came afterwards. The first was the unintentional neglect by nursing staff to take footprints, handprints, and a lock of hair from Jacob before his body was sent for cremation. While my heart still sinks at the thought that I was denied even those small but tangible mementos, I understand it to be a case of human error, the result of a busy, overworked staff. “But that’s no excuse,” the nagging*

*voices say in my more bitter moments. True. But I cannot dwell on it, we cannot go back in time and change it. All that can be done now is to do whatever I can to help ensure it doesn't happen to others. Hopefully, constructive criticism and suggestions will get much further than bitter thoughts.*

*The second problem we encountered was also a result of overworked staff and staffing shortages as well as human error, and it had a lasting impact on the choices we made about planning for more children. Jacob's initial diagnosis was a rare genetic disorder with a 25% risk of recurrence, and another 25% chance of passing the genes on to a child who would then be a carrier of the disorder (and could have their own problems when having children of their own). The doctor involved in the diagnosis was not 100% certain and sought out second opinions on some of the diagnostic tests that had been performed during the autopsy. About 10 months after Jacob died we decided to pursue adoption while we were waiting for the second opinion. We were uncertain about the risks involved in having more of our own biological children, and knew that the adoption process could take years. Through a series of errors, it took 14 months to discover that the tests had not made it to the doctor who was to give the second opinion, and another 8 months to get the final opinion on Jacob's diagnosis. Twenty-two months after Jacob's death we received the final diagnosis, trisomy 13. It's a much more common disorder with a much lower risk of recurrence, making our chances of having healthy, live children significantly better. If we had known that sooner, our decisions about trying to have more children would have been very different and would have been accompanied with much less fear.*

*Looking through my computer files, I find a scathing letter that I had written (but never sent) to the parties involved, asking for changes to be made, explaining how the errors and time delays affected our lives, and offering to help in any way that might serve to prevent similar problems for other bereaved parents seeking answers. Excerpts from my personal journal tell some of the story of how we were affected by the errors made (note: Jacob died in September 1999).*

*December 2000: ...Why, when I love children so much and have wanted them for so long, why am I the one who has to face the terror and uncertainty of whether it will happen again?*

*February 2001: I called the doctor's office in January and they had not yet received a report from the doctor doing the second opinion. They told me they would get back to me - they pretty much told me "don't call us, we'll call you". I'm ignoring that, and I'm planning to call today and get very pissed off if they tell me to be patient. At this point, since we've already decided to begin trying to have another baby, the only thing we want the second opinion for is to let our*

doctors know in the event that it does happen again - basically so they know what to expect and can plan for any early interventions to save the baby, or plan surgeries, or whatever. We'll continue trying to get pregnant until May, and then we'll have to stop since our "window of opportunity" will be closed, and I'll have to complete my degree.

Throughout this whole fiasco, I never expected a comforting, definitive answer. I probably would have been able to come to terms with the first opinion last year – but we were told to wait for a second opinion, and then we were left hanging. I have been extremely patient, probably too much so. I know the waiting list for these opinions is more than 14 months – but for God's sake, can't they make an exception for those of us who are grieving and need some closure? I know that is probably selfish of me – I know what waiting lists are like in the health care system, and I know that the professionals' hands are often tied – and that they hate it as much as their patients do. But don't they understand the pain that grieving parents go through, being left dangling with the promise that an answer will come?

July 30, 2001: Finally, 22 months later, a nurse from the doctor's office called today to give me the gist of what the doctors now think about Jacob's diagnosis. They now think it was trisomy 13 – which is more common and has a much reduced risk of recurrence (1%), and there are ways of testing both of us for the inheritance issue. I'm still too stunned to say much more on this. The anger has subsided a bit, for now, and I'm feeling a little more positive about the good news part of it all. But I don't understand how the doctor could have missed a more common diagnosis like that. All the pain and grief and worry that could have been prevented if only they had gotten around to our case sooner! We could have had another baby by now.

August 1, 2001: ...Part of my anger at the latest news is that I feel like a year or more of opportunity has been stolen from us. With everything that has happened, I'm still having a hard time realising that it is finally almost over and the news is good. I can't get past all of the time that has been lost and the anger at getting stuck in the system. I know in a few weeks I will be happy about the news, but right now I have to grieve another loss. We could have had another baby by now. I have every right to be bitter and angry for a little while.

§

**Stacie**

I don't like the fact that you get those 3 options at the hospital

**Myrna**

Did you get that too?

**Stacie**

Yeah.

Like you can.. pretty much leave it here  
and let us deal with it,  
or you can have the mass grave.

**Myrna**

Yeah.

Why would they even *suggest* that?  
(*What did they call it again?*  
*Something like 'shared burial area'*  
*I don't think it even dawned on me*  
*what that meant, at the time*)

**Dan**

Yeah, "We'll just throw it  
in the incinerator"

**Stacie**

Or you can do it on your own..  
I think.. they should be able to judge

**Myrna**

yeah.. they used to do that, the incinerator..  
and 30 years ago you never got to make a choice

**Stacie**

Well, now they give you a choice,  
but that's awful.  
It's an awful choice

**Myrna**

a stupid choice to give you

**Dan**

I know my grandfather  
worked in housekeeping  
at a hospital for 35 years  
And he said, you know,  
well, that was one of his jobs was.. the incinerator!

**Myrna**

oh, God  
(*Who comes up with these ideas?*  
*These are babies' bodies, for God's sake.*  
*If someone suggested doing that*  
*with an older child's body, there'd be a public outcry.*)

**Dan**

And he said it was just terrible!  
But.. that's 40-some years ago when things  
were a *lot* different. But yeah, it's hard to  
believe. And everybody says,  
"Oh, 40 years ago, everybody was *tougher*  
than they are today."

Well... yeah and no. I don't know.  
I don't know how time makes a difference.

**Myrna**

I talked to a woman who it happened to 35 years ago,  
and.. she went through severe depression all her life..  
Like.. *tougher*?  
Or the world expected them to be tougher?

**Stacie**

Exactly.  
That was back in the days where you stayed married  
no matter what, you worked no matter what,  
you just *did*.

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Stacie: We actually *just* got her headstone this August. 'Cause we had made some pretty... very quick decisions. I don't know, it's almost like you're pressured to do this. And after the person would leave, and we'd be thinking, well, we never even asked much, you know, and everything we asked for, the person kind of said, "oh yeah, but this this this, and if you bronze it, and it's a flat marker~" So they left, and I'm looking at this piece of paper going, "That is the ugliest thing I've ever seen! And we've just agreed to *pay* \$1300 dollars for it!" You know, because you make such rash decisions, just to get it done.

So finally we just dropped it completely. We had her cremated, and then buried her later on. We didn't bury her until about 7 months later, because I didn't want to bury her until I knew for sure Aaron was going to live. Because if something would have happened, I would have wanted them together. You know, they were born together, they were.. together. So it was June before we finally buried her. We chose a little country cemetery, where some of Dan's family are buried. We wanted her out there because of family.

Dan was able to have a little bit of closure on things, because he went out and actually dug the grave himself. That's what we did, we did everything ourselves. Dan's dad made this beautiful toy chest. And it was like a coffin, but it was a toy chest. And we picked up her ashes, and they had her in a nice box, in a red velvet bag and everything. And then, it was just family and friends, close friends. And we all put something in the box, whatever we wanted. Dan wrote a poem. He says he didn't have anything to give a little girl except for what he had in his heart. So he wrote a poem. And I put in my pink teddy from when I was a baby. A little baby girl. My pink teddy bear. Dan's brother bought her a silver locket. Like everybody just put in whatever they felt like, like I think Dan's mom made a porcelain doll, or a rag doll or something. My mom had knit a blanket. Everyone put everything in the box, and then Dan read his poem. And then I read the poem that Dan's best friend, James, wrote us. It's the most beautiful poem in the world.

And then we just put it all in, and.. buried her. There was a lot of *love* put into everything that went on that day. We did everything exactly how we wanted to.

And this year, based on a whim, I went and stopped in at a little tomb-stone place, *almost* outside of town. I thought, you know what, I'm feeling good about this now. I can walk in there now, and I can *not* cry while I'm saying *exactly* what I want and *why* I want it that way. Like there's specifics *I need* to represent... you know, because if you don't *know* the child, you can't say, "oh, well, they loved football, so if you put a little football.." The treatment I got there was *perfect*. I didn't want anything extravagant, I just want something that marks her. She told me the price, and everything, *everything* was perfect. They had the perfect emblem, as soon as I saw it in the book she showed me, I said "Okay, you have to do it for me." It's titled "The Twins." And it has the little girl twin behind the gate of heaven, with a halo, and a little boy twin entering. And it has "Heaven" across it. You know, and I thought, the twins, that's so perfect. Aaron on this side, her on that side. And the little saying is, "No tears past the gate." Perfect. But, it took me 6 years to finally feel, okay, this is what I want.

Dan: I'm going to remember her in my own way too. I'm getting a tattoo for her, that's going to be the way that I honour her memory. I'm getting it done right over my heart, a wooden cross, grass, roses. And it's going to have, "No tears past the gate" on it. That's going to be my little way of remembering her. But it's all part of the healing process. I look at it another way too, like to go ahead and bury her was a step towards closure. It was quite an elapsed time-frame there when we buried her, and then it took us a long time before we got the headstone. That was another *step* towards closure. And putting the headstone out there is going to be the final step, pretty much. See, I don't know if I could have *done it* right away. And I think that's why I put it off. I don't know if it was intentional, or if was in the back of my mind, you know. It seems like *everything* takes a *step*. And sometimes it can be a very *long* step. Like I just didn't *feel* right about putting the headstone out there before, but it *has to be* done. I want to get it *done*. I think I'm ready to do it now. But after this evening, I think we'll probably make a trip there this weekend. Bring her a bunch of flowers. Let the boys bring her some flowers. It's still really tough, going out there, you know. Um.. that's no excuse...

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*Dan leans over to take a sip of coffee. Everyone is silent for a moment, each lost in their thoughts. Dan sits back again and stretches out his legs before continuing.*

Dan: But ah... that's... that's pretty much our story there. And ah.. like this, the healing process is still going on.

Myrna: Yeah, I was going to say, how has it changed, how is it over time, you know?



Dan: Um.. birthdays are hard. Birthdays are hard, because-

Stacie: *(interrupts)* It's such a double emotion, you know.

Dan: Yeah, you've got to be, you've got to be happy, because *(mimics an excited voice)* "Oh, Aaron, you're turning 6 today!"

Stacie: You made it to 6, you know.

Dan: And then you go out, and you bring flowers to the cemetery, and you know, *(says in a quiet, sad voice)* "You would have been 6 today." You know. And that's.. that's really hard.

Stacie: The first birthday, that was really hard. 'Cause we had so much that year. We actually buried her in June. And then we got married in August. And then November was the first birthday. And.. we didn't know that so many people had made it out to the cemetery. It was actually quite touching. *(A dog barks and whines outside. Dan leaves the room to let it in, and he can be heard a moment later telling the puppy to settle down. Stacie ignores the commotion and continues talking.)* But the birthdays are still very hard. Christmas.. because it was so close to Christmas. Like, *oh*, that first Christmas, I was... like I actually got so mad at Dan because he didn't buy me a bread maker. *(Stacie says this with a grin and a tone of voice suggesting she thought this was a stupid thing to be fighting about. Myrna laughs.)* Or, I didn't think he bought me a bread maker. Like, it's a stupid thing, and we're fighting about it.

Myrna: But the emotions are just flying high, eh.

Stacie: Well, my thing was.. I mean, it's a stupid bread maker, go buy it! Like, haven't I asked for enough and not got it this year?! You know. And I.. honestly was very upset with him about a bread maker. *(laughs)* And I think.. depression-wise.. I was probably in a deep depression for about a year, year-and-a-half. And I wouldn't admit it. And.. now I can look back and say *(She makes a noise like she suddenly realized something that was obvious)*

Myrna: It's hard to tell at the time, eh.

Stacie: *(laughing)* Pretty depressed back then. But at the time.. no one could tell me. Like Dan and two friends that were with us through everything, we'd be playing cards one night, and they'd bring up something, and I'd say, "What're you guys talking about, I'm fine." You know. And now I look back at pictures and stuff, and.. you know, like I put on a bunch of weight, I wasn't sleeping right, I wasn't eating right. And then when I finally thought I maybe was out of my depression, I put myself on these diet pills, I'd take them, and they'd hype me up for an hour, and then I'd pass out on the floor, like I'd.. just pass out, 'cause I was so exhausted. And I actually tried doing that for *quite* a few times. And ah.. then, come the end of the depression.. you know, it was probably close to the end of the depression, I had actually convinced myself that I didn't want to be married to Dan. That.. the only reason we got

married was to have something good come out of that year, you know. And we actually did end up separating over it. *(laughs softly)*

Myrna: Did you? For very long, or~?

Stacie: 18 months.

Myrna: oh, wow

Stacie: It was actually awhile. But I.. convinced myself that.. you know, I didn't want to marry him! You know, I just wanted something good out of that year and that's it, type thing. *(Dan returns from tending to the dog, and comments on his pants being dirty from the dog jumping on him. Stacie looks up briefly and continues.)* Looking back now, I can tell it was.. I probably took it harder than I... pretended I didn't.

Dan: She was in total denial of everything

Stacie: Well, yeah

Dan: I was watching her flush her life down the drain, and she wouldn't listen!... you know. It was getting.. just ridiculous!

Stacie: Oh, my house, everything, like there'd be stacks of dishes, like if you came over for coffee I'd have to go, *(she makes a sweeping motion with her arms across coffee table)* you know, and make room on the table. I didn't clean, I didn't leave the house. I took Aaron to his neonatal appointments and that was *it*.

Dan: Yeah. I'd come home, and she'd be sleeping on the couch. And the kids would have the house just totally destroyed. I'd wake her up and go, "What are you doing?!" And she would *jus-st freak out*.

Stacie: I actually told him one night, "I like my food cold" *(Everyone laughs.)*

Dan: Yeah. She said, "Well, let's have a barbecue." We were in a lot of trouble by this time, you know, the two of us, our relationship. And.. I was trying to-

Stacie: *(interrupts)* Yeah, 'cause this was already after I told him I was pretty sure I only got married to have something good come out of that year.

Dan: I was trying to hold things together. And ah.. so I, *(takes on a mimicking tone)* "Well, I'm going to do a barbecue and do this and that and everything." And I go ahead and I do this nice barbecue and everything. She.. was passed out – and she wouldn't *sleep*, she'd just *pass out*. 'Cause she would go on these.. crazy..

Stacie: And I did, like at the time I was working, but it was a very part-time.. 2 days a week, you know, like I wasn't working that much.

Dan: Yeah. But she was sleeping, and I had supper all done, you know, and I.. go wake her up, and I said, "Well, you're supper's cold." *(mimics a witch-like voice)* "I like my food cold."

(*laughter*) She just screamed at me and everything. And we were.. we were in a lot of trouble there. And ah.. eventually it did lead to us being separated for just about 2 years..

Myrna: How did you work that out with the kids? Kind of juggling, or~?

Stacie: (*sighs*) No, I, I don't know, at that time especially, I think he backed off more than anything, because.. I was like, "These are mine," you know, "I'm leaving." At the time, I think I was still.. (*laughs softly*) pretty much in my depression. And I think it almost scared him.. to not let me just have my own way.

Dan: *Oh* yeah

Stacie: And have full custody. You know, like.. he.. kind of had more of an insight as to-

Dan: (*interrupts*) And then, then.. like *I* handled it all the wrong way too. I did a lot of things that I shouldn't have. But ah.. I was to the point where she had been just.. *haywire* for so long, and then finally she's like (*makes a noise/gesture like she just suddenly left, gone*)

Stacie: And I wouldn't admit it. That was the biggest thing.

Dan: Yeah! That was the worst part. You know, and there'd be me and my best friend and his wife, and we'd be sitting there saying, "Look!" And she would just, (*makes noise like 'you don't know what you're talking about'*) "Nothing's wrong with me. Look, I'm losing weight." "Well, you haven't eaten for a week!" You know, stuff like that. And it was just, it was *insane*. It was *total* insanity. And then, by the time that she was through with all of this, and she moved out, and took the kids, and.. everything, I just.. *I* went off the deep end for awhile myself. She walked out the door with the kids, and then it all went (*makes a noise like air going out of a balloon*) There was a lot of.. anger, a lot of hurt, a lot of.. bitterness, and everything else, and~

Myrna: Yeah. So how did you make it through all that? Back together again and~

Dan: (*pauses and looks at Stacie*) I honestly don't know. (*laughter*) We.. went for so long and-

Stacie: (*interrupts*) Back together again, that one's easy. I mean.. it.. pretty much dawned on us, even separated...

Dan: Well, eventually, it was like, "What the heck were we fighting about anyways? What was so terrible?" You know, and it was..

Stacie: Yeah. And it was stupid little things too, like when you tried to move on with your life... it just didn't matter. Like if I said, "Okay, well I'm going to maybe go on a date tonight." And if I was at the bar with a guy.. I would leave that guy sitting at his table to go join Dan at his table. You know, nobody else was worth... more to me than he was. So then it just became the point of, "Why are we even *pretending* that we're separated?" You know, we'd tell everybody "Oh, no, we're not together anymore," and we were together every Valentine's

day when we were separated, every Christmas party, *any* special time, we were each other's date for that special time. (*laughs*)

Dan: Then we got back together, and I got mad and quit my job 2 days later. (*laughter*) I was off work for just over a month. *That was rough.* (*laughter*) Yeah! "Welcome home honey!" (*laughter*) "I don't have a job, I'm going to be a bum for a month."

Stacie: I do think in a way though, the separation *did* help us. It got us each.. our own..

Dan: Well, it turned me into an alcoholic for 18 months. That's what I did, I hit the bottle hard, and~... And it finally scared me enough that I smartened up. Ah.. got to the point where I could go to the bar on a Thursday night, drink 24 beer between 8 o'clock and 2:30 in the morning, and still get up at 6 and go to work in the morning. And.. that was another thing that scared me, and, I thought, if I keep going like this, I need~ *She's.. she's my rock.* You know. And without her, I fell apart. I did. I'm not ashamed to say it. I went.. *ju-st rig-ht* off the deep end. I did *everything* wrong. I, well, I screwed up 2 good jobs. You know. And *that's* not me. I worked from 14 'till 25 at the same place. After that, all of a sudden it was bang-bang-bang, I can't do anything... But ah... everything worked out in the end, and ah..... (*looks at Stacie*) honestly, I don't think we've ever been happier.

Stacie: Well now we're really happy. See, I'd seen a counsellor.... what was it, a couple of months after we had separated? Just because my doctor referred me, because of.. the separation, and.. all that stuff.

Dan: I'd been trying to get her to go see somebody for *months*, previous to all of this, and, (*mimics a sarcastic, unreasonable, childish voice*) "There's nothing wrong with me." You know.

Stacie: That's pretty much when.. I started.. because I went back to school for my career and everything while we were separated. Everything I had done was after we were separated.

Dan: Well the thing was, for *months* on end I tried to get her to go and see somebody. (*mimics an unreasonable voice*) "No. There's nothing wrong with me, nothing wrong~" And as soon as we broke up, "Well I want us to go see this guy, and I want us to go~" You know. And then all of a sudden, it was all.. gung ho, "Let's go." And then I'd finally say, "Okay, let's go." And she'd say, "Well no." And it was just.. it was a game to keep pulling me back in, eh.. (*Sounds exasperated. Stacie and Myrna laugh*) And it was, it was *cr-a-a-zy*, insane. (*Stacie and Myrna laugh*) God! I wouldn't wish it on *anybody*.

Stacie: (*laughing*) But I finally did go, a couple of times.

Myrna: Yeah, yeah, on your own? (*Stacie nods*) Yeah.

Dan: And I probably should have been in A.A., and~ Oh-h man. I did it all, you know. It was just *dumb*.

Myrna: So how did.. that end? I mean, like, did you.. get help from friends and family, or did you just kind of.. on your own, or~?

Dan: No, we just- (*sighs*)

Stacie: We got back together. And it ended.

Myrna: Just~ yeah? And then it just.. worked out.

Dan: Yeah. We were just, one day we were ah-

Stacie: (*interrupts*) He was like that when I met him too, he drank really heavy, and then..

(*laughs*) once we started dating, he quit. I'm a good anti-alcoholic commercial I guess.

(*laughter from Stacie and Myrna*)

Dan: I should say I *was*, I guess I would consider myself.. an alcoholic. But ah, it seems like when I'm with her it doesn't ah~.. If I'm *by myself*-

Stacie: (*interrupts*) But he didn't drink, like he actually handled himself.. he *shocked* me when everything happened with Reanne. He really did. The way he handled himself, the way he knew *exactly* how to speak for me. Like when they were asking about an autopsy, and what to do with the body, I was *out*, unconscious. And he knew, like *don't* cut her. And *yes*, cremate her. He knew that's what I would want.

Dan: Yeah. Well we were pretty firm on.. on our beliefs, together, and..

Stacie: Well we both knew, like we both want to be cremated, so, probably, I mean, we never talked about the children, I mean..

Dan: (*interrupts*) Yeah. You're not supposed to outlive your children, you know.

Stacie: You never, in a conversation, say, "Well, what if something ever happened with the children?" It's like, (*laughing*) of course you don't say that! You know, like it's not something you discuss, but we knew what we wanted done with each other, and that this way would.. be the best.

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Stacie: We like to say that Reanne gave her life for Aaron. That before they both got too sick, and before we lost them both, she decided to let everyone know something was wrong. Which, if she wouldn't have started my labour, no one would've known, 'cause Aaron was way up there thinking the world was his oyster, he had no idea anything was happening! So if she wouldn't have done something, I could have lost both of them with that infection.

Our situation wasn't like anyone else's, I'm sure. Dan had the added stress of *me* being sick. And Aaron was a steady reminder, daily, that there should be two of them. And the

*clothing*, when I got out of the hospital! Everything that year, every store I went into was based for twins. So I would see the little sailor suit on one side, and the little sailor dress right beside it. I mean, it was probably just me picking it out, you know how you never notice babies, and once you're pregnant it seems like everyone around you is pregnant. It could have been that, but everywhere I went it was just non-stop... little girl's dress that matched the little boy outfit sitting right beside it. And it was like, "Oh-h, that's so cute," you know. And that too, like not only being robbed of a child, but being robbed of the special feeling people with twins get. You know, you have that special, "Oh, twins!" you know. Like.. getting robbed of that, too.

Dan: You know how they say twins have a connection? I remember after Reanne was buried, we went out to the cemetery, and we had the kids. And just *minutes*, 2 minutes maybe, before we got to the cemetery, Aaron started crying. And he cried and cried and cried. And of course, we got out, and went to the gravesite. And when we got back in the car, he cried and cried. And there was nothing wrong, he wasn't hungry, he didn't want a soother, he just cried and cried and cried. And by the time we got about a ½ mile away, all of a sudden he just stopped. And to me that's.. I think he *knew*. You know, and he was still so tiny. And I think he knew. You know, they say that twins have a connection.

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Dan: (*pauses and looks down at his hands, lost in thought*) Ah.. the first couple of times.. we went out to the cemetery, Stacie was stronger than I was. And ah... but you know, it's daddy's little girl. (*laughs softly*) You know. What.. with daddy and his little girl, you know, it's that age old~ And ah.. I guess I feel cheated because my little girl was taken away from me, before anything~ And ah.. I still find it really, *really* tough to go out there. And ah.. I don't know, it's been six years, and I can't remember *a day* that goes by, in that *entire time*, where I don't think of her *at least* a hundred times a day. You know, and.. I can honestly not think of a day where I don't think about her. I think about her every day, dozens and dozens of times. And *today*, I knew this interview was happening. And ah.. to tell the honest truth I was in a... bummed out mood all day. You know, like, (*looks at Stacie*) you probably noticed when I got home I wasn't too talkative. And it was hard to stay upbeat at work. I was in a.. pretty rough mood all day long today. Even just *songs* you hear on the radio, you know, it *all*.. reminds you. And ah.. I'll probably continue to be in a.. bit of a bummed out mood for, you know, another day or so. I suffered from depression pretty heavily as a teenager.

Myrna: Did you? Yeah

Dan: And ah.. sometimes it comes back to bite me, and~

Myrna: Have you had much over the past 6 years, or~?

Dan: Um.. (*sighs*) I've learned to deal with it. I was younger, 15 or 16 I think it was, when they figured out that I had depression. Ah.. 'cause it runs in my family. And finally, I think I was 16, I asked my mom what it felt like to be depressed. And I went to the psychiatrist, I had the pills.. and I *didn't* like it. You know. I *didn't like it* at all. I don't want to be hopped up on drugs just so I'm happy! You know. This is garbage, and~ And.. I managed to ah.. I haven't been on any medication for 10 years now.

Stacie: Ever since you met me (*laughs*)

Dan: Yeah. Um, there's, there's..

Myrna: (*grinning at Stacie*) You're just.. a miracle cure, eh? (*Stacie and Myrna laugh*)

Stacie: I am (*laughs*)

Dan: There's--, well I will admit that there's probably several times where I *should have* done something.

Stacie: Yes.

Dan: Um, because, well I have a...

Stacie: temper

Dan: quite a terrible temper.

Stacie: Which is why I'm impressed he got through all the things with Reanne without.. any.. ending up in jail. I was very impressed.

Dan: Well, I had to patch holes in the walls at the house.

Stacie: Yes. You did.

Dan: I punched a bunch of holes. Um... I'm just happy I didn't break my hand or something, hitting a stud. But.. no I, I punched a bunch of holes in the walls, and.. like I say, it's lucky that I wasn't standing in front of the doctor when he told me, because I might still be in jail. (*laughs*) Um... well, mind you, I could have pleaded temporary insanity on that one, for sure? (*laughter*)

Myrna: (*laughing*) oh, I'm sure, yeah

Dan: I, I would have took his head off.. oh-h, boy. But ah.. yeah, like I say, there's probably times I should have been on something. But.. now.. I don't know, I.. I think about her now, and ah... it doesn't hurt.. as bad. You know, I'm, I'm...

Stacie: Yeah, it's one of those.. it's not a hurt. It's a joy.

Dan: Yeah, I'm *happy*. I'm *happy* thinking about her. You know, and ah.. it makes me feel good.. I don't know, it seems like..... well, she's my little angel, now, you know. And ah..

Myrna: mm, yeah.. so a more peaceful kind of feeling, eh



Dan: Yeah. I feel like, you know, things happen, you know. And sometimes I think that she's watching out, and making sure nothing happens. 'Cause like this past summer, my mom and dad should have died. It was scary. Me and little Aaron were at the lake. This guy lost control of his truck with a load of hay on it. Me and my little guy were right behind Mom and Dad, and I'm watching them, and I thought they were dead. It was insane. But all of a sudden, everything just straightened out, and the guy got it under control, you know. And.. she's the first person I thought of, I thought, "Oh my God, she just saved Mom and Dad," you know, and I don't know, I think she.. watches out for us. 'Cause I did some really *silly* things when Stacie and I were apart. And I think, (*laughing softly*) maybe she's the reason why I'm still on earth. You know, to make sure that Mom and I got back together again. But ah.. (*begins crying*)

Myrna: little guardian angel..

Dan: She is, she's my angel, and.. I miss her and I love her (*cries quietly*)... It's pretty tough.

Myrna: yeah-h... never ends, eh

Dan: No, it never will.... I'll be... 80 years old, and still crying about her (*his voice breaks, and there's silence for a moment as he sobs. Myrna's eyes well up with tears, and Stacie reaches out to touch Dan's arm.*) You think you're.. you think you're past it..... (*crying*) and then.... I haven't cried over her in a long time. But tonight...

Myrna: brings up a lot, I know

Dan: Yeah, it does, but it feels good too, you know. I feel like, I don't, you know.. (*laughing sob*) I've been holding onto it for so long, you know

Myrna: yeah, yeah.. you can only hold it so long.. yeah.... I had ah, one mother say to me that.. she cherishes those times when she breaks down. And.. you know, that's.. part of.. her child, and.. you know, she feels closer to her sometimes then.

Stacie: Yeah. That's how I am. When I have a bad day and.. it hits me, it's like.. "You know, baby girl, you were the first thing on *my* mind today." (*laughs softly*) Like, you *know* it. Obviously I'm very close to you today, I'm.. thinking about you today..

Myrna: Yeah. Sometimes I miss when.. I don't have those times for awhile, you know? Like.. get a sad movie, and then have a good cry. (*laughs*)

Stacie: Yeah. It's true. Because then you'd be feeling.. almost guilty, like.. okay, why haven't I.. got upset lately?

Myrna: yeah, yeah, start thinking you're forgetting her..

Stacie: You know, is it.. am I starting to forget about you? You know, that's~

Dan: Well, you know, I grew up as a skinny, scrawny little kid. (*Wipes his eyes, but his voice is strained with emotion as he talks*) Teased, and.. everything, all my life.. And after I got away from school I let my hair grow long, I got earrings and tattoos, and.. everything. And try and be the big guy.. look tough. "Look, be scared of me." You know, I don't want to walk around.. scared of you guys all the time anymore. (*crying*) And I remember going out to the cemetery... (*laughing/crying*) big black steel-toed biker boots and my leather jacket (*Dans voice breaks as a sob forces its way out*).. and I cried like a baby. (*laughing/sobbing*) I laid down there, and I just cried... (*The room is silent for a moment aside from Dan's sobbing. Myrna and Stacie sit quietly with tears in their eyes.*)

Myrna: yeah....pretty hard to be the tough guy when.. something like this happens.

Dan: It is... (*crying*) I don't care anymore, you know. I don't have to be tough.

Myrna: yeah-h.. doesn't matter anymore, eh... yeah.

Dan: I was there for her. That's all that matters. (*Continues crying, but able to talk without difficulty now.*) It didn't matter how long my hair was, or how many tattoos I have, or.. how much beer I can drink..

Myrna: Yeah... it's a hell of a lot stronger to be able to do that for her..

Dan: (*says with his voice breaking/crying*) I miss her so much. (*crying quietly for a moment*)..... I made a promise too, that I-

Stacie: (*Interrupts, looking at Dan with a grin on her face.*) I didn't think you'd bring that up.

Dan: -I feel bad about everyday.

Myrna: What's that?

Dan: Well, my little girl.. I love long hair... That's why Stacie has long hair. And I always did. And I promised Reanne that.. (*crying/laughing*) I would always keep my hair long for her... Look at me! (*Rubs his shaved head with both hands as he laughs and cries at the same time.*) I'm bald (*laughter*)....

Myrna: (*laughing and wiping her eyes*) When did you cut your hair?

Dan: About a year and a half ago. I was working in an RV shop, and.. I got my hair caught in the creeper, and came home with blue in it..

Myrna: oh, no (*laughs*)

Dan: You know, and everything else, and grease, and dirt. And ah.. (*laughing*) one day I sat down in the backyard and told Stacie's dad, I said, "Shave my head." (*laughter*) And ah.. I feel bad about it, you know, I think about that often, I'm supposed to.. I made my little girl a promise, and she's the last person on earth.. that I wanted to break a promise with, but.... (*takes a deep breath*) sometimes, things just.. (*laughter*)

Myrna: You've just got to do it

Stacie: I'm sure that she understands (*laughing*)

Dan: I'm sure that she's okay with it.. (*laughter*) but I still feel bad. I have my ponytail in a plastic bag. (*laughter*) I still have some long hair for her. Um..

Myrna: (*said with a grin*) Well, you still have your long hair then.. just not on your head

Dan: yeah

Stacie: I didn't think he'd bring that up (*laughter*)

Dan: And, sometimes I don't think about it but, you know.. it's funny, I don't know. But.. yeah, it's so hard.

Myrna: Yeah-h.... I know one of the reasons I wanted to... or, when I was planning out what I wanted to do.. a lot of the research out there is strictly about mothers. And I'm reading this stuff, and I'm thinking, you know, just based on.. my husband's reaction, why do they make the assumption that it's harder for mothers? Where is the stuff about fathers, you know? So I said, forget that, this is going to be.. whoever wants to talk to me.

Stacie: Exactly

Dan: Yeah, I tell you, Daddy hurt a lot. You know.

Stacie: It's almost, I would think, *harder* for a man. Because they're used to being the boss. They're used to being in control..

Dan: Everything was out of control, and-

Stacie: they're used to being tough. "Leave my family alone, don't hurt my~" Like, they're used to being the protectors.

Dan: Yeah, and then you're standing there, and you're helpless.

Stacie: And then to stand back and watch it, and not be able to do a damned thing about it.

Myrna: Yeah. And then afterwards, the man's still forced to kind of take over, 'cause, you know~

Stacie: Yeah. And another thing is, just people's attitudes from the time men are little is, "Oh, just suck it up! Quit the tears you baby." You know. Whereas women, we can break down on a bus with complete strangers, and, "Blah-h," about everything. And blubber about it, and everyone pats you, and.. you know. Whereas a man, they look at you like~

Dan: The way I look at it, I get my 3 days.. you know, of grievance time. Suck it up, walk back into work. My wife's in the hospital, my son's in the hospital, my daughter's dead. My other boy is.. with my parents, you know. Or her parents, or wherever.

Stacie: He's somewhere (*laughs*)

Dan: You know. And to walk back into work, and I've *known* these people forever. My dad has worked there since 1968. So I've known them since.. pretty much the day I was born. And to

walk back in and face all those people.. (*his voice breaks slightly with emotion*) after everything that had gone on. That was probably, next to everything that went on with her, that was the *hardest* day I had, after all of it was done, was to go back to work. You know, and ah.. suck it up... and of course it's hard, because *everybody* wants to come and say, "I'm sorry." And... then they also want to say, "Congratulations." (*laughs softly*) Because I had a double whammy thing there, (*slaps hands together*) you know, I had the *two.. at once*, and..

Stacie: Yeah. See, that's what I found, with Brendan, our oldest son, I was in the hospital and *flowers* and *cards* and all this stuff appeared. I got *nothing*, for Aaron.

Dan: No, that's right. Because nobody knew what to do! You know!

Stacie: Because nobody knew how to handle it, like do we send her a bouquet of condolence flowers? Or do we send her a bouquet of congratulations? Like, a couple weeks later, my Grandma and a bunch of people sent some stuff. Stuff did start appearing. At Aaron's baby shower, of course, then we got all the cards and everything, but.. the time in the hospital..

Myrna: Just silence almost, eh

Stacie: Exactly, people didn't know what to say, like.. do they just walk in and say, "Congratulations!" and you look at them with, you know, "What are you saying?! I lost my daughter, Congratulations?! *Thanks.*" (*said with sarcasm*) And that's the thing, 'cause people don't have enough.. information, enough... knowledge to know what to say in a situation like that!

§

Dan: I remember how much I scared the poor nurse, in the hospital right after the Caesarean. They of course rushed the babies off, and when Stacie's lung collapsed they said, "Oh, we've got an emergency, you have to leave now sir." And they kind of shuffled me out the door. And I walked out the door, and I leaned against the wall. And I was excited, I was happy, I was scared! Everything just all *hit* me, and I stood there, and I was *ju-st crying*. And the nurse, I think her name was Chrissie, I still remember, she was at the nurses' station and she came *running* down the hallway, and she had tears in her eyes by the time she got to me, saying, "Oh my God! What happened?!!" And she's hugging me and everything. And the two of us stood there bawling. I'm like, "Nothing's wrong!" Crying like a little girl. *Oh-h* man, I never shed so many tears in such a short amount of time. I was scared, I was happy, I was excited, I was nervous, I was~ Oh, it was *unbelievable*! I never felt such a *mixture* of emotions. And then, finally, I get everything, I *think*, under control, and then I get this big *bombshell* dumped on me, that Reanne passed away, and then it started all over again. And, oh-h my *God*.

I was pretty freaked out too, 'cause it was like.. here I am, I finally, like before I knew that.. she had passed away, and.. everything, I get home with my son, and I'm sitting there with him, and he's just *crying*. He wouldn't stop. Oh, my God, it was just nuts. You know, but what do you do? He's.. so confused, and he knows that something's wrong with mom, nobody's telling him nothing. He's 3, he doesn't understand. Cried and cried and cried and cried and cried and cried all night. *God*, I was just going *insane*. But what do you do? You've got to let him do it. Right? And.. I'm sitting at home with him, and he's in my arms just *crying* and *wailing*, and *tears* and *blubbing* and *snot* and.. You know! And I'm holding onto him, and *I* started crying, because I thought "My God"... you know. "They could give me a phone call, and it's just going to be you and me, buddy." That's how scared I was. I was thinking that I lost *all three* of them. And it was just going to be me and my boy, you know. And that was~... and then I get, *oh-h-h*, you know, and then you're already *thinking* that way, and then you get a *phone call*, and.. *oh-h-h* man. And then all that, that.. *scared* and *anxiety* and.. *joy* and.. everything, and then it all turned into *anger*, and I just *exploded*. *Oh-h-h*, man, it was just~... I wouldn't wish it on my *worst enemy*.

If it wasn't for my best friend and his wife... For a couple of days there, I went and stayed at their house. He's my best friend of 20-odd years. You know, you have friends, when you're in school and everything, and then after school it seems like, no matter how *great* of friends you were, you drift apart. I have a dozen friends like that. But James, we met when I was 10, he was 11. And that's over 20 years. And we hardly go a *day* without talking to each other, still. And they're the kind of people that you can talk to about *anything*. They're never prejudiced, you know. They're the *best* friends. Sometimes it's better to have friends to talk to than your own family.

Stacie: James and Lisa can't have children. And they've tried everything. So they're very good, because, well, they don't have the *loss* of a child, but they have the loss of not being able to *have* a child. So they totally understand, they were so in-sync with us, with everything we were going through, it was amazing. That loss, of not being able to have a child, made them *so aware* of what we were going through. They knew when to back off, and when to say, "No, I'm not going to back off," and hug you... They were probably the ones who handled it the best.

Dan: The twins were born 4 days before my birthday. And my mom and dad, *of course*, were trying to be strong for me and everything, they knew that I was just completely falling apart. And they planned a surprise birthday party for me at the farm, and James and Lisa showed up and everything. And it went along for awhile, and I remember they brought out my birthday cake, and that was *it*. I said, "I can't do this." And ah.. nobody got upset, nobody told me, you know,

suck it up. But James and I went downstairs and we sat on the bed in my old room, and I cried. I actually, I think I... punched him in the arm a couple of times and he just said, "Let 'er go, man." And he was *encouraging* me, he's like, "Come on! Scream and yell, be *angry*!" You know, like, "Get it *out*!" He says, "If you've got to punch something, don't hurt your hand. *Hit* me." Oh-h, my *God*! This guy's just throwing himself at me, you know, like... And that's how *good* of a *friend* he is. And ah, I don't know how many times.. I think I went and stayed at their house that night too. 'Cause I was a *wreck* that night.

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**Dan**

When we found out we were having twins  
I think my dad was really happy  
my dad has twin sisters

**Stacie**

Your dad talked to me that one time, and he was blaming it all on himself.  
Because his family's always had a bad run of twins.  
Either one survives and one doesn't.  
And when his sisters who *are* twins survived,  
their mother had a nervous breakdown right after they were born,  
and they were taken away and put in foster care.  
So because all this bad stuff had always happened to his family,  
because of twins..  
It was at Christmas time, we were downstairs, and.. he broke down,  
and basically told me it was.. his fault.

And that's what I couldn't believe is.. like everyone's holding it inside,  
nobody wants to say what they really feel,  
because everyone's blaming themselves

Like my dad blamed himself, because he really wanted a granddaughter  
*Bad*. That's *all* he wanted.  
First time I was pregnant, "Oh, it better be a girl."  
Next time I was pregnant, "It better be a girl."  
Every time I'd get pregnant, "Oh, I need a girl."

**Dan**

Yeah. I wanted my little girl too, you know

**Stacie**

And he's.. a very.... *God* man, he believes in God a lot.  
So he thought God taught him some lesson.  
"Here's your granddaughter, now I'm taking her back."  
To prove humility or something to him.

**Dan**

I think one of the hardest things was watching *my* dad.  
Because my dad.... he left home when he was 15 years old  
because he'd had enough.  
His dad beat him with a belt buckle, ran off for months on end.

My dad is a *strong* person. He's come from a family of a string of alcoholics.  
And he's *made* something of his life. He has a beautiful farm, and a house,  
he's held down the *same job* since 1968!  
And.. my dad lost a *finger* to a hay baler! Never even said "ouch" hardly!

And... one of the only times I can remember my dad crying  
was at his mom's funeral, my grandma's funeral.  
That was one of the only times I can ever remember seeing my dad cry  
Until.. this happened.  
And *that* was hard on me, because..  
here's my dad, he's, he's *my rock*.  
Dad has always been there, he's so tough.  
He lost his finger! He just about lost a couple other fingers.  
And.. all these accidents, you know, farming, you get hurt and everything.

And I always thought my dad was *invincible*.  
And then to see him break down.  
And.. *that was.. that was hard*.  
That really hit me like a *ton of bricks*.  
You know your parents, you live with them all your life.  
But I really got to *know* my dad that few days.  
And ah.. it was almost scary.  
"Wow! I've known you for 20-some years,  
I didn't know this about you."  
And it's... rough.

**Stacie**

Like my dad said, it's the most amazing thing  
that the tiniest little girl  
could make *so many* men,  
so many big men,  
Crumble.  
And it's true.

**Dan**

Yeah, she brought us all to our knees.

**Stacie**

She was.. the very *tiniest* little girl in the world  
and she crumbled all of those huge men.

**Dan**

Me, my father-in-law, my dad  
We always considered ourselves strong,  
Like, "Jeez, I knocked off half my finger..  
Didn't even say ouch, went to the house,  
got stitched up, went back to work. No big deal.

**Stacie**

All these tough guys (*laughs*)

**Dan**

Broke three ribs, had to sleep sitting in a chair for a week  
'Cause I couldn't breathe when I laid down. Big deal.



But this.. just dragged us all right down to our knees.  
And, and, and it's.. the *power*.  
That was something else  
*That's* the thing you don't forget.  
You're *never* going to forget.

**Stacie**

It's just that amazement that somebody who's been in the world..  
so little time..  
Such a little person  
can have such an effect on so many people.

82

Myrna: Do you feel like you've.. changed? Either or both of you, or~?

Stacie: I have.

Dan: Yeah. (*sighs loudly*) Um..... I don't know, I... I'm trying to be a.. a better person. Um, I forgot.. and lost my way before. Um.. but when I start.. thinking that I'm losing my way, I, I think of her. And... she kind of puts me back on the straight and narrow, and.. and ah..... she's, she's, she's a Godsend, a lifeline. Um.. a guardian angel. She's the power behind the throne, kind of thing, you know. She's sitting there, she's, well, that's what I called her is, "my little princess". You know, ah.. um.. daddy's little princess.

Stacie: Me, I'm more.. I don't know... it's hard to admit, but before I was a more happy-go-lucky person. Took day-by-day, you know, who cares, whatever, whatever comes. And *now* I'm more cynical, definitely. Definitely. More.. I don't find myself as giddy as I used to be all the time. I mean, I don't think I'll ever be that way again. And.. crying. Like, before, you know, women's stuff, I'd be (*mimics sobbing*) And *now*, I almost have a thing of.. *nothing's* worth crying. Like, *my* tears, I shed for my daughter. If *you're* not on the level of my daughter.. you ain't worth my tears. You know, 'cause to me it almost feels like, well, if I cry over just any little thing.. it kind of deadens.. what those tears meant for her. So it's got to be a *pretty big* thing to bring me to tears. So that part of me changed, I'm not as sensitive anymore. (*laughs*)

Dan: And that, it's almost worked.. *opposite* for me. Sometimes I'll be sitting, and I'll be watching the *corniest* T.V. program, and something will happen, and I'll just--, you know, it's all I can do to keep myself from crying. You know, and it seems like I've become more emotional since. It's really bizarre, like you'd be watching, and it'd be just something really *dumb*.

Myrna: Oh, you should see my husband and I, crying over commercials, it's~ (*laughs*)

Dan: (*smiling*) That's just about how bad it is! You know, you're sitting there, you'll be watching some *crappy* show, you know, and all of a sudden (*mimics sobbing*)

Myrna: (*laughs*) We're like, "Okay, change the channel," you know

Dan: Oh, yeah, you know, this isn't good. You know. And it's ah... even some days at work, ah, something will hit me hard, eh. Just out of the blue. You know, like stuff just, *bang*, gets in your brain, eh. And ah.. then I just go for a little walk, and get myself under control, you know. (*laughs*) Go have a cigarette in the back or something, eh. There's one guy at work, he's really perceptive of all this kind of stuff, eh, and he always knows, you know. And that's hard too, because you can't hide nothing, eh. (*mimics a frustrated voice at this. Myrna laughs.*)

Stacie: See, and before I was a good hider. I could put on that smile and.. work it. Now – I don't even bother. People are like, "What's wrong with you?" you know. "Nothing. I just don't feel like talking," you know. It's actually.. it's made me definitely a *stronger* person. It *definitely* changed my attitude on the children I have. Like, not that I didn't love them 100% before. But I've noticed since.. everything happened.. like number 1.. Aaron, oh, for the first year of his life, the kid could do anything. Because.. I didn't care. I mean, people would say, "Oh, well he's eating that Kleenex box," you know, or whatever. And I'd be like, "The kid lived for me. Leave him alone." (*laughs*) You know. Like that's the only thing I asked of that child. I asked him from the day he was born, "Just live." And he did. So.. I didn't think the kid owed me anything. (*laughs*) So he, (*laughing*) he did get pretty rambunctious after awhile, because mom didn't care, you know. It'd be like, "Oh, Aaron's tearing that display down." "Oh well.. Aaron lived," you know. (*laughter*)

Dan: "That's okay, he's next to God in our house (*laughter*)

Stacie: Yeah.. (*laughing*) that's exactly what it was. So you kind of had to.. lessen your expectations on the other child, because then you're double-

Dan: (*interrupts*) Yeah, well Brendan, he had some problems with us, he had some issues, and he was really resentful of Aaron

Stacie: Yes, he was

Dan: He was, oh, *terrible*, oh my God. Um, and also, it didn't help, when we brought Aaron home he was on oxygen.. Um.. so we-

Stacie: (*interrupts*) He was *so* little, and needed *so* much~

Dan: He was so tiny, and he needed so much attention, eh. And Brendan was *really* resentful of that. And he still is to a point. Um.. he really likes to pick on Aaron, which we *really* try to discourage 'cause Aaron's so small and frail. Um.. but I remember, yeah, one time, Aaron comes out of Brendan's room, and he's just *screaming*. I look and he's just wearing a pair of pants, he had no shirt on. And he's just got these *claw* marks down his back. (*mimics an angry parent's voice*) "What the heck were you doing?!!" "I was tickling him." (*laughter from*

*Stacie and Myrna*) He's got him down on the floor, and he's just scratching, you know, (*mimics a growling voice*) and getting back at him (*mimics growling*) you know. So then you're, of course, (*mimics anger*) freak out, "Go to your room! Sit on your bed!" (*mimics an angry voice*) And you're just all furious, eh. "Why would you do that?!" So then he's in trouble. And then right away, (*mimicking tone*) pick on the baby. (*Stacie and Myrna laugh softly*) You know. And, and, it's... (*makes a noise of frustration*) you know. And Brendan still remembers a lot of that. And it's hard because, you know.. what do you do? We try not to treat them any different, you know, like Aaron, now that he's old enough, he gets in just as much trouble for doing something stupid as Brendan does, you know. And it's *equal*. between the two of them. You know, if one does something really stupid, it's like, (*mimics angry parent voice*) "Go to your room," you know, but-

Stacie: (*interrupts*) but you still have that underlying.. "You're my miracle." That's my way of thinking, I mean, if I hadn't *at least*... gotten Aaron out of that deal.. I wouldn't be here today to do this interview. You know, 'cause I almost went over the brink with just.. Reanne. Had it been *both* of them..... I couldn't guarantee that I wouldn't be... either dead by my own hands, or in some insane asylum.. twiddling my thumbs right now, (*laugh*) you know. So I look at him as my.. you know, my *saviour*, he kept me going, he.. kept me together.. even though I was falling apart...

80

**Dan**

They say parents should not outlive their children.  
And I agree with that. Very unnatural.  
It's not the way the world should work.

**Stacie**

When you lose a grandparent.. you're upset, *definitely*.  
It hurts. But... you can.. understand it,  
you can.. walk through it, and say, well, of course,  
you're *supposed* to be there when your grandparents die.  
I'll be here when my *parents* die.

**Dan**

Yeah. Watching my grandpa suffer  
with his cancer and everything, it was hard, you know, but-

**Stacie**

You don't expect to ever outlive your child  
You don't expect the first time you're going to buy a gravesite,  
it's because it's for your *daughter*.  
That kind of hit hard.  
You know, we're buying a family plot  
because we've lost a child already.

**Dan**

Not because we're planning for the future!

**Stacie**

We were in our early 20s!

**Dan**

We're, we're planning for.. the present

**Stacie**

And we have to buy a plot.. to bury a child  
That kind of hit hard.

§

Stacie: At the time of the surgery and everything, I was supposed to have my tubes tied.

Because I would have left a mother of *three*. And at the time of birth, they didn't know if *either* child would survive, so they didn't tie my tubes. Because they thought, "She might decide later that she wants to try again." And then after everybody was home about a year, you're like, "Oh, it'd be nice to have a little pit-patter around."

Dan: "Buy a dog." (*mimics an irritated voice. Myrna and Stacie laugh*)

Stacie: We actually got in a couple arguments over it, because I was pretty firm on trying again.

And um-

Dan: (*interrupts*) And I didn't want to. I couldn't do it again

Myrna: Couldn't go there again, yeah

Dan: No. Couldn't go there.

Stacie: And he'd also.. I guess, him and my dad had an agreement.. that ah.. if he ever did this to me again, (*laughs*) ever got me pregnant again, my dad would kill him (*Myrna laughs*), and that was *fine* with him. He agreed that yes-

Dan: (*interrupts, smiling*) I'd probably be in a wheelchair now

Stacie: (*smiling*) He agreed that, "Yes, if I ever get her pregnant again and put her through this, you just have your way with me." (*Myrna laughs*) And I had doctors telling me too, that, you know, each time now it's just getting worse and worse, like, "You *can't* keep doing this." And then one night we got in a fight.. we were laying in bed and we were talking about it and we got in this *huge* fight... and he called me *selfish*, and.. you know, all this other stuff, you know, "You're so worried about having another baby, you don't even care about the two you'd be leaving behind, and me, and~" So that was added stress. And then, finally I gave up the idea because.. it just dawned on me one day. If I have a boy... I'm going to be heartbroken. You know, I don't want to get pregnant to have another *baby*. I want to get

pregnant to have a *girl*. Period. And if I have a boy.. I'm not going to want it. You know, I'm going to be so neglectful. It could be different if it happened, but this is the way I felt

Dan: It's your mindset

Myrna: yeah, yeah, that's right

Stacie: And if I have a girl.. she's not going to get to be herself, because I'm constantly going to be trying to.. see Reanne in her, *live* Reanne through her.. you know, ah.. catch myself every now and then, "Oh, Reanne, would you bring me--, oh, I mean~" You know, I couldn't do that.. to.. a child. So I thought, either way I'm looking at this, I'm trying to do this for my own benefit. So.. no, let's just end this, (*laughs*) so we can't have any more kids.

Myrna: So, did you.. was that okay with you then, after, once you'd made the decision, did it feel right then?

Stacie: Yes. Yeah, totally.

Dan: Yeah, I went and got fixed.

Stacie: When we'd decided not to have anymore kids, I went to my doctor and said, "This is our decision." And he told me right there, he said, "I will do Dan. I will get Dan set up, I will have a urologist," he said, "but, with the stunt you pulled last time, and ending up in ICU," he said, "I'm not putting you under for nothing." He said, "It's got to be something pretty important." (*laughs*) For a 26 year old, I've had way too many surgeries.

Dan: I didn't *fight* it, I'm not like most guys, (*mimics a macho voice*) "Oh forget it." (*laughter*) You know, a lot of guys would be like, "Oh, if I have to do that, I'm going to have another kid." I would never do that to her. Even if something, God forbid, but something should happen and we split up again, and never got back together.. I would *never* have a child with anybody else anyways! You know, I wouldn't want to do that! I wouldn't do that to myself, and I *especially* wouldn't do it to her. You know, and I wouldn't want to do it to *my* kids *either*.

Stacie: Yeah, that was another thing we found, when we were separated. You know, 'cause we were separated long enough to have started separate lives. And if either of us were seeing somebody, and the prospects of children came up.. and of course, well, he's had a vasectomy, he can't. And I'd say, "No, it would kill me, I can't." (*laughs*) You know. And.. the biggest thing would be, no! Like, I couldn't do that to him. If I started this whole new little family, and this guy *lucked out* and gave me a girl.. I *could not* do that to Dan. And I knew it!

Myrna: mmhm. Yeah, so it was all there, that.. you're kind of meant to be together

Stacie: Exactly. (*Dan agrees*) Like there's no way I could hurt him like that. Like, how could I walk in and say.. you know, "Oh, by the way, look what this man gave me that you couldn't."

Or.. you know, to me, it was just too much of a slap in the face to even.. *bother*. Like I've got my two children, I *love* them to death, and that's all I want is the 2. So.....

Dan: (*Takes a drink, and leans back again on the loveseat*) But, I think we've gotten.. way far off the subject here.

Myrna: No! that's okay! (*laughter*)

Dan: We're sitting here blabbing

Myrna: No, that's good, this is good

Stacie: No, she'll listen to it later, she'll say, "Actually, this all runs in somehow." (*laughs*)

Myrna: It's *all* comes together, yeah

Dan: yeah, I guess so

Myrna: The one thing I'm wondering is um.. you know, like I was saying with the grief stuff that's out there, they say, "Oh, you.. *get over it* after a year, and then it's back to normal." This whole "get over it," did you hear much of that? (*Dan scowls and starts to speak but stops again.*) And, you know, what do you think of that? (*She laughs at the look on Dan's face.*)

Dan: I think it's *crap*, personally. Like I think it's a total load of garbage.

Stacie: I love the way they can give you like 7 steps to grief that you go through – anger, and then you go through denial, and-

Dan: (*interrupts*) Yeah! How do you know what I'm going to-

Stacie: (*interrupts*) how do you know that everyone goes through them the same way?!

Myrna: Exactly.. nice neat little steps, eh. (*Dan agrees*)

Stacie: I didn't hit anger first! I can honestly admit that. I didn't!

Dan: I did. (*makes a noise like it happened instantly*) Right now. Bang. (*Myrna laughs softly*)  
Zero to~.. just all-

Stacie: (*interrupts*) Apparently, 4 months later, I did say something to my family doctor about the gynaecologist. 'Cause the next time I needed to see a gynaecologist, he referred me to someone else. And I thought, that's really *weird*. Why is he referring me.. I've seen this gynaecologist's office *forever*. So I asked him, I said, "Well why am I going to this clinic now?" And he said, "You don't remember that time you were in here, shortly after you got Aaron home?" And I said, "No..?" He said, "You threatened.. you told me that if you ever saw that gynaecologist again, you'd kill him." (*Stacie says this with a grin. Myrna laughs.*) And I didn't remember saying that! (*laughing*) Like I didn't think I was that open with my family doctor, "Oh yeah, you send me back to him, I'll kill him!" (*laughter*) I *honestly*~ And he remembered I said it, so he wouldn't refer me back..

Dan: Yeah, and the grief counselling they have is a total load.. of tripe.

Stacie: I believe that.. you know, all those feelings, you do go through. But for them to be able to pinpoint exactly the order they go in,

Dan: Yeah, and how many days apart it's going to be

Stacie: And the thing is, you're sitting here looking at this piece of paper that tells you the order they're supposed to go in, and how much time it's going to take, and you actually look at this as if it's like the written word.

Dan: Yeah! "Oh, I have to feel this way today,"

Myrna: mm, yeah, "so I'm abnormal if I'm not~" yeah

Stacie: When your 3 months is up and you're not over that stage yet, and you're supposed to be moving on, "Oh, well what's wrong with me?" Or you hit another stage, *before*? Or you *double*-stage it, where you're still in the middle of *one* when *another one* hits!?

Myrna: Yeah, it's just so simplistic, yeah (*Dan agrees*)

Stacie: And you look at this piece of paper and go.. oh, well~..

Dan: No, they don't know, they don't know... they-

Stacie: 'Cause personally, the grief... I mean, I get the grief when my 2 children are *wrecking* this house. And in the back of my mind I think, "Oh my *God*! What would I have done with 3?" And then of course, the guilt sets in. Because there – I've just.. admitted *why* I lost her. You know, like.. God *knew* I couldn't handle 3. You know, that's *6 years* later it still hits.

Dan: These people that do this, I can't say it for all of them, *but*.. how many of them have *gone* through what *we* have gone through? Um.. probably *none* of them, more than *likely*. 'Cause if they *did*.. they would take all these pamphlets and toss them out the window!

Myrna: mm, exactly, yeah

Dan: And ah.. I think that somebody like yourself.. you know, ah.. would be a *great* benefit.. to people like us. You know, and ah.. like I would go and talk to people *myself*! You know, if I *could*. I don't have any *training* or anything- (*said with a note of sarcasm suggesting, "what would I know about it"*)

Stacie: (*overlapping*) I think.. it's more helpful.

Dan: ..but.. I've *been* there. I can understand what you're going through. I still *feel* the hurt, obviously, and.. you know.

Stacie: And like, while we're talking, when you say, "Oh, yeah, yeah, I~", I'm not just looking at you and thinking, "Oh, what do you know about it!?"

Myrna: mmhm, yeah, you just.. get it

Dan: Yeah, because.. you know, *you're* so easy to talk to about this.



Stacie: You agreeing, or you saying, "Oh yeah, been there," you know, it's.. Yeah! You have. It makes it a *whole* lot different than some woman, or some man, giving me a list of ways things should be dealt with. And then you ask them, "Well do you even *have* children?" "Oh, *no*, I'm not even married." "Well, what do you know about the topic?!"

Myrna: yeah. Even if they mean well it just--, they just don't get it

Dan: Yeah, it's ah.. mean well or not, I think you're doing more *harm* than *good*. Um.. but no, somebody like you.. I think would be a *great benefit* to.. *to* the public. I don't, I'm not *sure* on how often.. like I imagine this is *quite* a *common* thing. It happens every *day* I'm *sure*. Um.. you can feel like you're-

Stacie: (*interrupts*) Although at the time you feel like you're the only one (*laughs softly*)

Dan: You *feel* like you're the only one, you know. And.. it.. you feel guilty because you think, "Oh, I'm being selfish," you know "I feel so *bad* for *myself*." But... you have the *right* to.. at that time.

Stacie: Yeah, that's the biggest thing, no one tells you that you have the *right* to be...

Dan: I had the right!

Myrna: yeah, yeah, exactly

Dan: To be angry and-

Stacie: You know, like if I want to be totally witchy one day, and scream at somebody, and~ See, like to be honest, the most help I had was from a publicly funded "Healthy-Mother, Healthy-Baby" nurse. 'Cause she *doesn't* have to come after you've had the baby. (*laughs*) But she showed up at my door after the baby was born. She actually came to see me just after Aaron and I both came home. And you know, she was asking me, she said, "Well how are you doing?" And I said, "Today I'm just not doing good. It's *not* a good day." I said, "Everything I believed in, everything I thought~".. you know, I'm a good person, I thought I was a good mother. You know, I thought God only did stuff like this to bad people. You know, and I said "Actually, today I broke down." And, I mean, I literally told God to.. take anything he wanted and *shove* it up his~ You know, I was *mad*. And she looked right at me, and she said, "Well you have every *right* to be mad. You have every right to feel *cheated*." She said, "And to be honest with you, from what I know about God, He's probably the best person to take it out on, 'cause he's probably the one who's going to forgive you tomorrow." And you know, it just made *so much sense*, I was like.. you know, like *no* counsellor, no five-step program.. she just listened, and said, "well, personally I think~"

Myrna: didn't tell you how you should be feeling

Stacie: Exactly. You know, she was just very good about it, and I thought, (*laughs softly*) you're not even supposed to be dealing with this, like, after the woman has the baby, you're supposed to say, "Oh, my job's done." (*laughs*) You know. I think the biggest problem with the whole *grief* issue is.. if you're grieving *anything*.. you're going to be given the *same* 7 steps at the *same* time. Grieving a *friend*, a *child*, a *parent*, a *dog*. It's the exact same steps. And it *can't* be. Like when a death happens *out* of order, grief *can't* be the *same*. *Anyone* knows that. And I think that's.. the *strangest* thing, that okay, they've put these steps on nice little pink paper, and they bring it down to a loss of a child level. But it's still the same, the exact same steps they're going to give you for your great-grandfather! And you were *expecting* your great-grandfather to go.

Myrna: yeah, there's something wrong with that, yeah

Stacie: And I think that's the thing, is it's not.. there's not enough knowledge out there that... it is.. *mentally disturbing* when things don't go in the order of nature. It's.. more *damaging*.. than I think people actually think it is.

Myrna: Yeah. You have to try and find some way of making that *fit* into your world, you know, it just doesn't~

Stacie: Exactly. Like you're trying to.. figure out, like this is supposed be the *start* of my life, not the *ending* of~ you know

Dan: They throw some.. some *pamphlets* at you. *Talk* to you for 5 minutes. And your world is supposed to be *all better* now.

Myrna: Send you on your way, eh

Dan: "Do this." (*slapping his hand on table*) And they turn around and walk away, and they leave you *alone*.. when you need somebody *the most* out of your *entire* lifetime. You've never needed *anybody* so bad since the day you were *born*. You know, and they just, "Here. Here's some books. If you want to talk to me, here's my card." (*said with a tone of sarcasm, disgust*) You know. Yeah, I'm going to *phone* you, and do this over the phone. No! You need somebody like.. like your best friend, that's willing to sit there and have himself.. *punched* in the arm because you've got to let something out or you're going to *explode*. You know, and he's encouraging you, "Come on! Just scream, yell, kick, bite, snap. Do whatever you want," you know. "Walk around and cluck like a *chicken* if it makes you feel better." (*laughter*) You know. And.. you need that. You can't just have somebody going, (*mimicking voice*) "Here, here, here, read this, read this, read this." You know, and, "If you're not feeling better in, you know, in 6 months, give me a call." Well.. "Sorry to have *disturbed* you!" You know. And it just, it makes you feel just.. alone. you know, and~

Myrna: mm, that's right. Um, actually, I should mention one thing about the grief *stages* and all this stuff. There actually is starting to be.. some really *good* stuff out there, research, counselling and everything. Um.. saying that, well, especially.. with respect to bereaved parents, that.. you don't get over it, you just learn to live with it. (*Dan agrees*) You know. And then, *throw out* the stupid stages, you know, you can be angry 30 years later, you can be.. volatile all the way through, I mean, it's *not abnormal* to be grieving years later. You know, and that's what the older theories tried to say, is that it's *abnormal* if you're not over it, you know, after a certain period.

Dan: No, no. It depends on the person. Ah, it depends on.. on the support you've had too. You know, from friends or family.

Stacie: And there's triggers, you know.

Dan: Yeah, there is, there's definitely triggers

Stacie: And like me, working at a doctor's office, I get too many triggers. Because you get some woman coming in, 'cause her social worker's bringing her in, and she's 9 months pregnant and drunk, and they're sending her to some home to have the baby so she's at least *sober* when it's *born*. And you're looking, you know, and she's going to have a perfectly fine, alive child. "Thank you!" You know. Like, *those* are the times when I get angry. You know, or.. people's children being taken away by social services. And it's like, okay, well where's the *justice* there?

§

*The tape recorder clicks off, signalling that we've been talking for more than 2 hours. I turn the tape over, and Dan and Stacie laugh about how long we've been talking.*

*"sh-shhh!" Dan mimics, "Shut up! I want to go home, you people!" We laugh, and I protest through my laughter.*

*"She's like, 'oh yeah, they take that 2 to 3 hour thing seriously,'" Stacie says, laughing.*

*"Hey, we'll go for another couple hours the next--, if we meet again." I say, wiping my eyes.*

*"If. Yeah, she's already planning to scratch us off the list." Stacie teases, sending us laughing again.*

*"No!" I protest, laughing, "If you want to, I mean."*

*We talk for a few more minutes, and they show family photos from when the twins were born. After awhile, Dan says, "But.. we should probably just let her.. get onto her next question here, and~"*

*"Well, actually, I think you've answered everything for now. I don't--, like after I've gone over everything I'll probably have some more questions, but~"*

*"We're pretty open people," Stacie laughs, "you probably realized that, huh?" Dan agrees with a laugh.*

*"Well, yeah," I say, laughing, "but, you know, I'm finding that.. that parents have.. like the story just **comes out**. You know, like you **don't have to** ask questions, you **tell** me what's important, I **don't** have to ask~"*

*Stacie cuts in. "Well you see, it's **bragging** rights. Like.. it **honestly** is. Like if someone was here asking me about either of my other children, I'd be 'blah blah blah blah blah.' And it's no different."*

*"yeah, yeah, it's your chance to talk about her," I say.*

*"Exactly. It's my one chance to~"*

*Dan interrupts. "We don't talk about her.. **a lot**. You know, everybody has their.. their inner feelings, and ah.. you know, everybody's very **content** with that. You know, and.. it's.. it's not something you just bring up at the dinner table, you know. It's ah.. it's an understanding. **Everybody** knows that **everybody's** thinking about her."*

*"Yeah," Stacie agrees, "and we're all comfortable, like if her name comes up, we're all comfortable with it."*

*"And everybody's fine with it, yeah, if somebody **does** mention her.."*

*"The **boys** are famous for it. Like Brendan will say something about.. 'oh, well, today in school... I had said, 'oh, no, I have a sister,'" you know. And he goes, 'I **can** say that, right?' We've never hid it from the boys. Both the boys know about Reanne. I mean, that shelf in our living room is pretty much hers. And if we go to the cemetery, they come. And I mean, everyone's comfortable with her name being mentioned. If Brendan says things like, 'I wonder what Reanne's doing right now,' like it doesn't **shock** anybody if it's brought up, it's~"*

*"Yeah.. well, and that must be nice for you too, that she's a part of your family.. all the time." I say, thinking to myself that when we have more children, I hope we can keep Jacob a part of our family in such an open, comfortable way.*

*"Yeah, and that's exactly what it is," Stacie agrees. "You know, she is a part of the **family unit**. She'll be in my family ring, she's.. Aaron's twin, Brendan's sister, they both know that. When asked.. you know, how many children do you have, I **do** have three. You know, like, this is the woman who wanted a girl," she laughs, "I mean, I'm not going to **deny** I had one now! You know. We **did** have a girl."*

*Leaving Stacie and Dan's house an hour later, the emotional and physical exhaustion overtake me. Somehow, though, the weight on my heart doesn't feel as heavy as it has after the other interviews I've done so far. I mull this over on the drive to pick up my husband from work before making the trek home to our acreage. Perhaps it was their humour that eased the burden of the grief-filled topic. Or maybe it was the overall feeling of peace that I felt in their presence, peace despite the never-ending grief. Their humanity, their honesty, and their strength as a couple inspire me.*

## 9. MY SEARCH FOR MEANING: MEANINGS, MEANING-MAKING, AND TRANSFORMATIONS

Scene: *It is the end of April 2005. Myrna is sitting at a large cluttered desk in a small home office. Two smaller desks form a U shape with the larger desk, and stacks of books and photocopied journal articles cover the surfaces of both of the smaller desks. Myrna stares at a laptop computer, switching between keyboard and mouse occasionally as she scans through documents. She looks up as the door to her right opens a crack. LeRoss, Myrna's husband, pokes his head through the door.*

LeRoss: He's asleep. (*Referring to their 16-month-old son, Caleb.*)

Myrna: (*rubbing her eyes under her glasses*) Good. He was pretty tired, wasn't he?

LeRoss: Yeah, he fell asleep faster than normal.. How's it going?

Myrna: (*Sighs loudly, with a scowl on her face.*) I'm never going to finish this final chapter. I

thought I'd be done by now! (*Her voice gets louder as she talks and reaches for articles and notes sitting next to the computer.*) I thought I knew what I was going to write, but now I don't have a clue. (*She waves the papers in her hand as she talks, and throws them back down on the desk in frustration.*) It's the meaning-making and transformations stuff. I wish I could just leave it at the stories. They're compelling and powerful and they speak for themselves. I think they'll achieve what I hoped they would – they evoke an empathic understanding of the experience of losing a baby. The stories *show* instead of *tell*<sup>13</sup> the reader about long-term grief over a perinatal loss. And that should be enough. But *no*, I have to tie it back to *theory* somehow. (*Said sarcastically. She is in full ranting mode now, and LeRoss puts his finger to his lips and gestures toward the baby's room. She lowers her voice, but continues ranting.*) I mean, the meaning-making stuff was so important to me when I wrote the proposal, and it *still* fits for me as a good description of what goes on during grief. But finding meaning and “creating something positive out of the heartache and agony of grief” was part of *my* agenda from the beginning, the meaning that *I've* created to deal with Jacob's death. It wasn't necessarily important to the parents when I asked them about it, although they all displayed meaning-making and changes even when they didn't directly address them. But how do I go into all of this without taking away from the power of their stories? (*As Myrna talks, her hands*

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<sup>13</sup> Arvey, 2001, p. 218

*gesture sharply with her words, and her voice rises again. LeRoss listens quietly, and then looks to the corner of the ceiling in the characteristic way he does when he's thinking deeply.)*

LeRoss: Well.. I think for me, when you talk about “meaning-making,” I’m not sure how it relates to my experience. What *do* you mean by “meaning-making” again?

Myrna: (*Sighs and nods her head as she answers.*) Yeah, that’s the problem, isn’t it? It’s an important concept, but it doesn’t necessarily resonate with bereaved parents as being something that relates to their experience, ’cause it’s such an abstract thing.. (*She pauses, looking toward the stack of articles and chapters on the desk.*) I guess I should clarify what it is again, first...



### 9.1 Meaning-Making Revisited

A number of bereavement researchers have considered the definition of “meaning” and a cluster of related concepts that have to do with the role of meaning-making in grief. Davis (2001) pointed out that a significant problem within this area of bereavement research is that “meaning” is often not defined clearly or consistently. He summarized the various definitions or conceptualizations that have been given to meaning, including: the ability to develop new goals and purposes and incorporate the loss experience into a reconstructed sense of self (speaking to the transformative potential of grief); meaning that is obtained at an emotional level (e.g., existential meanings, such as feeling at one with the universe); and the explanations people arrive at for the event (e.g., God’s will, fate), which come about through the process of considering the loss within the framework of one’s existing worldview or implicit assumptions about how and why such events happen.

From these various definitions or aspects of meaning, Davis focused on two construals of meaning in his research: “meaning as finding benefit” and “meaning as making sense of the loss”. Making sense of the loss involves trying to explain and interpret the event by considering it in terms of one’s existing worldviews or rebuilding threatened worldviews. In contrast, benefit finding is triggered by the loss experience, but has little to do with the events as such; rather, the benefits a bereaved person finds have more to do with his or her experience of suffering in general than with the particularities of the loss itself. Davis suggested benefit finding involves maintaining or rebuilding one’s threatened sense of self in the face of being forced to redefine central aspects of one’s sense of self. Talbot (2002) similarly separated meaning-making into two “interrelated pathways: meaning-making that addresses issues, circumstances, and questions about the child’s life and death, and meaning-making that focuses on the survivors’



beliefs, worldviews, life purposes, and hopes for the future now that the child has died.” (p. 79) Attig (2001) further separated out the various conceptualizations of the search for meaning by distinguishing between *meaning making* and *meaning finding*. Meaning making refers to the conscious and active process of reinterpreting and bringing new meaning to one’s experiences, actions, and suffering; and meaning finding refers to a more passive, less conscious process of becoming aware of and accepting meanings that are well-established or that arise spontaneously out of grief and suffering. The interplay of the two processes, Attig suggested, permeates the overall process of “relearning the world” after a loss.

The concept of transformations of self is one aspect of meaning-making that occurs for some bereaved individuals. As indicated, Davis (2001) used the term *benefit finding*, which he divided into 3 categories: growth in character, change in life perspective, and strengthened relationships or increased sense of connectedness with others. Calhoun and Tedeschi (2001, p. 158) opted for the term *posttraumatic growth*, which they also divided into 3 domains that are consistent with those of Davis: changed sense of self, changed relationships, and changed philosophy of life (existential and spiritual growth). In his study of caregivers who had lost a loved one following a long illness, Davis found that while sense making was not significantly correlated with changes in emotional adjustment to the loss, benefit finding had a significant influence on a person’s emotional adjustment over time. Davis concluded that these two forms of meaning-making represent distinct psychological processes and issues.

In considering the theoretical roots of this new wave of grief theory, Neimeyer (2001) provided a broader understanding of meaning-making or meaning reconstruction. The concept of grief as a process of meaning reconstruction following a loss is based on constructivist metatheory, which suggests that it is not the “brute facts” of an event that determines the meaning it has for us, but our constructions of its significance (Neimeyer, 2001, p. 263). A relatively recent extension of this line of thought is that narrative or storytelling is a “powerful ordering scheme” that human beings use to make sense of our lives. That is, by our very nature we compose narrative understandings of our life stories, and meaning reconstruction represents the struggle to *incorporate* important life events into our stories; at other times, meaning reconstruction involves *changing* the presuppositions or assumptions that provide the framework of our stories when we are faced with experiences that are unexpected or do not fit within our existing narrative understandings of our world.

Based on these various descriptions and definitions, I suggest that the definition of meaning-making or meaning reconstruction can be made clearer if it is conceptualized along one of two lines: the *content* or products of the meaning-making process, that is, the meanings

that are made or found; or the *process* of making or finding those meanings. For example, Attig's (2001) distinction between meaning making and meaning finding is illustrative of the *process* of making or finding meanings, whereas Talbot (2002) is referring to the meaning *content* in her distinction between meanings addressing the death and meanings addressing beliefs and worldviews. For the sake of clarity, I have distinguished between meanings based on content, with the processes of meaning-making or meaning-finding being the pathways to these meanings. I have defined *meanings* as the thoughts, understandings, beliefs, perceptions, construals, realizations, and interpretations that a bereaved parent assigns to their experience of losing a baby. I suggest a distinction between *meanings* and feeling a sense of *meaningfulness* (or *meaninglessness*) in life, in that a person might ascribe a variety of meanings to their experience but still feel a sense of meaninglessness (Thompson & Janigian, 1988). Meanings are both cognitive and emotional, in the sense that they are based on intellect but are often emotionally laden and emotionally derived. Meanings are unique to the individual, they are varied and complex, they can be positive or negative, and they are influenced by the individual's life experiences, their personalities, and the ideologies of their social and cultural context.

The three broad categories of meanings that I propose, which are similar to Talbot's (2002), are: (1) *Meanings that attempt to make sense of the baby's life and death*. These meanings include causal attributions about the death and explanations for the death such as fate or God's will, as well as meanings that attempt to answer a host of concrete and existential questions that help to make sense of the baby's death within the context of an individual's larger life experience (Nadeau, 1998). From a process point of view, arriving at these meanings can either be grounded in existing worldviews and assumptions or reconstructed ones, and can be an active/conscious or more passive/spontaneously arising process. (2) *Meanings that make sense of one's grief* and all that it involves and awakens. These are the meanings that help the bereaved in learning to live with the reality of the loss and their grief. Again, these meanings can be made by either a process of incorporation within existing understandings of the world or re-evaluating and reconstructing new meanings to explain one's experiences, and can be an active process (such as choosing how to proceed with one's grief) or a more passive process. (3) *Meanings that reflect the self-changes brought about by grief*. These are the meanings that can result in the bereaved person discovering a different perspective on life, establishing a changed identity, and recognizing changes in their relationships (Davis, 2001; Calhoun & Tedeschi, 2001). However, by self-changes I am referring to both the positive and negative changes identified by the bereaved, rather than only positive changes that result in personal growth.

Scene: *Myrna and LeRoss have moved their discussion to the kitchen, where Myrna is washing and LeRoss is drying dishes as they talk.*

LeRoss: Okay, so those are your definitions of what meaning-making is. But.. it still seems kind of.. *(he gestures with his hands, searching for the right word)* ..abstract. How about for yourself – how have you made sense of your experience?

Myrna: Well.. *(stares out the window as she gathers her thoughts)* I guess one way I've tried to make sense of it and find peace is through my spirituality. Like when I read the book, "When Bad Things Happen to Good People," and the author<sup>14</sup> talked about bad things happening at random rather than being caused by God, and we seldom have control over them, and nor does God. And out of those bad things we can become bitter and angry, or we can learn and grow from the experience. It's what you do, how you respond, that determines whether any good can come out of a bad situation. At that point in my grief – I think it was in the first year – that made a lot of sense to me. It led me to think actively about what I could do to bring about positive rather than negative meaning. And my spiritual search for meaning has continued, and my meanings keep evolving and changing as my faith changes or deepens.

LeRoss: Okay, so meaning can be found through religious beliefs.. for some people. For me, religion didn't give me any meaning, it only made me more confused and angry.

Myrna: Right, but it's not just about religious beliefs. Meaning-making can come about in other ways, like how I was feeling so guilty in the first weeks after Jacob died, and then Carol talked to me about her baby's stillbirth, remember? *(LeRoss nods.)* She had a lot of the same feelings, wondering if her baby would have survived if she'd gone to the hospital sooner. Well, one of the original meanings I was giving to my experience was that I was to blame, and if it hadn't been for the fact that I knew Carol *and* she had a similar experience *and* she invited me to talk about it, I would have accepted that self-damaging meaning for who knows how long.

LeRoss: *(nodding)* Right, right. *(He looks out the window, pausing as he ponders over his thoughts. Myrna watches him, waiting.)* What you just said reminded me of something. When you had me read a draft of Judi's story, I remember the part where she said that parents whose children die as toddlers or teenagers can't understand what she's been through because at least they had memories, and all she has is a brief nightmare of a memory. When I read that, it hit me as a totally different way of interpreting that issue. I kind of liked how she turned it around, because for awhile I measured grief the other way, that parents

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<sup>14</sup> Kushner, H. (1987) When bad things happen to good people. New York: Random House

with toddlers grieved more because they had more memories. But then again, it's kind of in a pissing contest – what do you win by winning? (*Myrna smiles and voices her agreement.*) So I guess that has been one of my meanings, that there's always somebody worse off. Not that losing Jacob wasn't a great loss, but I'm thankful for what I do have, or more embracing of.. more appreciative of what I have. And it also gave me a better understanding of how close to death we really are. We think we have control over things, like with modern medicine and actions we can take to prevent situations... but now I realize how little control we really have. It showed me the frailty of life and that we need to appreciate what we do have.

Myrna: (*speaking fast, excitedly*) Yeah, exactly. Really, all of this stuff that we're talking about is meaning-making. And the stories are *made up of* the unique meanings each of the parents made. Meaning-making is the way we arrive at our perceptions of our experiences. And how we perceive our experiences affects our grief. Like Judi – the meaning she came to, and stayed at, was that she was responsible for her baby's death. That she *killed* her baby. The important thing about meaning reconstruction, and the reason I want, or *need*, to include a discussion of it, is that some parents *do* get stuck at a point of meaninglessness and hopelessness, and the meanings they come to are all negative, and the only way to emerge from the meaninglessness is for them to shift their meanings, or reconstruct, or reframe... Does that make sense? (*LeRoss nods encouragingly.*) That's the reason I brought Irene's story into Judi's – because Irene found a way, after many, many years, to do just that – to reconstruct the meaning she had given to her experiences. She went from telling herself that everything about her life, her choices, *herself*.. was shameful... she went from *that* incredible degree of shame, to accepting that yes, she made some "dreadful mistakes,"<sup>15</sup> but that her actions and choices were understandable given the cycle of abusive relationships, trauma, buried grief, alcohol abuse... how did she say that? Let's go back to the office for a second. (*She goes to the computer and types a few words and searches through a file. LeRoss follows a minute later.*) Yeah, here it is. After her son died, she buried the grief and she came to a point where she wasn't treating herself very well through her choices. She said it got:

almost to the point where I couldn't *find* a partner or a person that *wasn't* abusive. Almost to the point that I *deserved* an abusive person rather than a good person.... And of course I wasn't good to myself, I did go through all the addictions. Not so much drugs, but certainly booze... but I think the drinking was not so much a physical addition for me, not so much an alcoholism at all, it was something else to put on top of these.. these things... see I realized, later, that that *first* situation was abuse. And, even the medical profession was.. abusive.

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<sup>15</sup> Quoted words or phrases throughout this chapter are direct quotes from the participants' transcripts unless otherwise indicated.

And then she went on to say that she came to recognize – what I would call reconstructing her meanings – that not expressing her grief affected her in all sorts of ways, physically, psychologically, spiritually, emotionally. And she was very angry with herself for letting all of these things happen to her, and she eventually realized – or shifted her perception or meanings – that in many ways, she had no choice. Especially with giving up her daughter for adoption, it was the best thing she could do at the time.. oh, and I like how she said this part (*reading from the computer screen again*):

And with that knowledge, I have to.. to let her go. And with my sons, I wasn't the best mother in the world. But I certainly was the only mother, the only parent they had. And I did my best.. at the time. And sometimes I didn't do my best at all. Sometimes I made.. dreadful mistakes. And did.. lots of things. But I can accept that now.

(*Myrna finishes reading and looks intently at LeRoss. She pauses in thought before continuing, speaking more slowly now.*) So, what Irene's story taught me, especially in comparison with Judi's, is that a bereaved mother can emerge from buried grief and utterly negative meanings about herself and her experience and come to self-acceptance and forgiveness – but only by shifting her perception or reconstructing the meanings she gives to her experiences. I think this is one of the most important things for helping professionals like counsellors, doctors, and nurses to understand about grief – really about any type of loss, but maybe about perinatal loss in particular, since it has been so ignored and disenfranchised in our society, which ultimately was the reason that many of the mothers I interviewed buried their grief in the first place. It's important for professionals who come in contact with the bereaved to understand meaning reconstruction as a key part of emerging from chronic grief, because even now, the message that parents who lose a baby receive is that grief is difficult, it involves some predictable stages or phases of emotions and reactions, but time will ease the pain. But for someone like Judi, that message completely overlooks the possibility of grief becoming chronic and unchanging because of negative meanings that a person becomes entrenched in. That's where counsellors with an understanding of the role of meanings in grief need to come in, to try to help a person identify and reconstruct the unique meanings they've given to their experience. (*Myrna stops with a sigh, her brow knitted.*) Am I making any sense?

LeRoss: (*Nodding.*) Yeah, I think so. So.. what matters for our long-term grief is how we perceive our loss, and some people need to reconsider their perceptions before their grief will subside?

Myrna: Yes! Oh, and the other thing I didn't mention, is that the meanings I was talking about in terms of Judi and Irene are very often *emotional* meanings, rather than simply a cognitive or intellectual understanding that needs to be challenged. Like with Judi, she knew on an intellectual level that it wasn't her fault, but on an emotional, grief level, the meaning she made that she was to blame was deeply engrained. And maybe some of it, too, is that in addition to reconstructing their meanings, they first need to be given the permission and opportunity to truly grieve.

LeRoss: Okay. I think you're right, that's an important message to include.

Myrna: Okay, good. Thanks for helping me sort out my thoughts.

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*Why? Why do babies have to die? There is no satisfactory or acceptable answer to this question. Even with faith in God, and a belief that, likely, things happen for reasons we will only know after our own deaths – even then, the answers do not satisfy the need to know why. Maybe that's why some parents looked at me as though I'd grown a second head when I asked, "Have you made any sense of it for yourself?" (Journal entry, April 2005)*

The parents I interviewed were often unable to articulate their thoughts on meanings when asked directly, or they sometimes denied finding any meaning in their experience but then proceeded to share the meanings they had considered<sup>16</sup>. I believe this occurred for a couple of reasons; first, because parents understood "making sense of it" as finding satisfactory meanings that eased their pain; and second, because meaning-making is the process they were engaged in *as they told* their stories, and is identifiable in *how* they told their stories as well as the specific conscious ways of making sense of an experience (e.g., finding a purpose or reason) that they could readily identify. Telling their stories the way they did, emphasizing some events, talking more generally about others, leaving out some parts but focusing on other parts – all these choices, whether conscious or not, demonstrated something about how the parents made sense of their experiences. In some ways, then, the meaning-making that the stories are composed of was perhaps more readily identifiable by me as a listener, and later as an observer reading the transcripts, than by the parents as the storytellers.

Deena, Andrew, Judi, Sharon, Dan and Stacie are clearly unique individuals with unique losses and circumstances surrounding their losses, living within the context of distinct social networks and cultural backgrounds. It follows that their meaning-making journeys were individually influenced by and contained within their distinctive characteristics and contexts. In this sense, they ascribed to uniquely individual meanings following the deaths of their babies.

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<sup>16</sup> Nadeau (1998) described a similar phenomenon among her participants.



These personal meanings are seen most clearly by considering their stories as a whole, which maintains their individuality and their distinct circumstances and social/cultural contexts. In another sense, meanings sometimes followed a common thread across the parents' stories, being contained within the same theme or emerging from a common meaning-making strategy or influence. In all instances, the meanings that parents attached to their experiences appeared to influence the course of their grief.

In the remainder of this chapter, I present the culmination of *my* personal search for meaning. My focus on meaning-making and self-changes reflects my pursuit of a clearer understanding of the experience of losing of a baby and the ensuing grief process, and thereby a better understanding of my own loss and grief. Ultimately, this is *my* story about my attempt to understand meaning-making – how it applies to my loss and how I incorporated what I learned from this project and these parents into how I understand my son's death, my grief, and my revised worldview and sense of self. Although my interpretive focus and choices were inevitably steered by my personal search and my subjective interests, I made every effort to bring forth the parents' most salient messages in the process.

This chapter, then, contains my interpretation of the 5 stories and excerpts from the additional 7 stories, through which I sought to understand better the meaning reconstruction process and self-changes brought on by a perinatal loss. The sections that follow focus on: (1) The personal meanings of Deena, Andrew, Sharon, Judi, and Dan and Stacie, which illustrates how each individual's unique circumstances and context influenced their meaning-making process, and ultimately, their long-term grief; (2) Common meaning-making influences and strategies across the larger group of 12 individuals' or couples' stories, which addresses the more culturally pervasive meaning-making themes that can provide professionals with a "framework for exploration" (Wheeler, 2001) of meaning-making brought about by perinatal loss; (3) positive and negative self-changes that parents experienced as a result of their losses and grief; and (4) the impact of meanings on the grief process.

## 9.2 Personal Meanings

### 9.2.1 *Deena's Meanings*

Deena's story portrays a woman who desired compassion and nurturance following the death of her baby, and instead felt emotionally neglected by a society and a husband who told her to forget about her son and get on with life. She is a childless mother who wanted to nurture a child of her own, but was forced to find other outlets for her nurturing instincts instead. Her stifled grief and thwarted motherhood eventually contributed to a long-term struggle with depression.



A gentle and unassuming woman, Deena's story was filled with subtle contradictions between her view of herself and what her story revealed about the person she was. While she seemed to view herself as fragile ("bad nerves"), her story nonetheless included examples of strength and assertiveness; times when it was necessary for her to take care of others, ignore her own needs for emotional support, and manage on her own. For example, Deena voiced her needs even during a period in history when assertiveness in women was frowned upon (e.g., she insisted on leaving the hospital after her baby died, instead of silently enduring the presence of other mothers and babies as was the expectation of the time; she purchased a grave marker on her own, despite her husband's attitude). She seemed unaware of these examples of strength and assertiveness, perhaps because her independence emerged out of necessity due to an unsupportive first husband, rather than by choice or desire. What she desired was compassion and nurturing while she grieved, which, ironically, she did not appear to receive in sufficient amounts until she struggled with depression. She saw herself as dependent on her second husband and mother because of her bouts of depression. Yet, she minimized the reverse role she played, that of caring for and nurturing these and other people in her life.

Significance of Her Loss: Like many other parents experiencing a perinatal loss, Deena's meaning-making was complicated by her loss and grief being minimized by her doctor and most of her social network. She felt alone with her grief not long after returning home. She tried to make sense of the lack of compassion and acknowledgement for her grief over her son, and later, the sense of loss with her miscarriages: "But I guess... maybe people thought I couldn't talk about it." Over the years, she recognized that perhaps it was her responsibility to broach the topic if she wanted to talk about it. She found it difficult, however, to make her needs known, to talk about her grief and her motherhood status. Her perception, the meaning she arrived at, was that others would view her losses as insignificant and not consider that she is really a mother. She expected to be dismissed by others as foolish if she raised the subject of her loss so many years later.

Despite being given the message that she should forget her loss and simply replace her son with another child, in Deena's heart and mind she managed to maintain a belief in the significance of her loss. She asserted her son's individuality, remembering and grieving for *him* specifically, and emphasizing that he was not replaceable. She did not passively accept the meanings given to her by others: "...everybody shut up... the door's shut.. but not to the one that's gone through it... You never forget." She also understood the psychological impact of holding her grief inside. She said that it would have helped her to see a counsellor, and that her depression "relates back, maybe, to some of that part too. Because... you carry it with you for so

long, and finally it comes out a little bit. You can't keep it under control all the time, it's in the back of your mind I guess."

On Being a Mother: Making sense of her childless mother status was a painful and difficult issue for Deena. She felt that people did not recognize or remember what she experienced, that her son existed, and that she was a mother to him as well and for as long as she was able. She perceived herself as being excluded from the mother "group" or "clan," and did not know how to (or could not) make herself a part of the group. She likely believed she would not be accepted no matter what efforts she might make to have her loss and motherhood acknowledged. The belief that everyone has forgotten her experience, her motherhood, and her son was most troublesome for Deena.

In seeing herself as a mother, Deena also took on the guilt and feelings of responsibility that many mothers have. Trying to make sense of her role in her son's death is an area where Deena's feelings and thoughts conflicted. She said she was not entirely at peace with thoughts that maybe she could have done something more for her son, if she had "paid more attention to him sooner." She called herself "naïve" and "dumb" for not asking more questions or insisting that something was wrong. Yet she also displayed faint recognition of her powerlessness as a woman in a paternalistic medical system, and perhaps some acceptance that she was not to blame: "But it--, my hands were tied."

Ex-husband's Reaction: Deena tried without success to make sense of her ex-husband's reaction following their son's death. Her belief that her ex-husband blamed her for their son's death could not be confirmed or denied because of his angry and cruel response to her attempts to initiate any discussion. The conflicted relationship with her ex-husband extended beyond his lifetime, because of his grave being placed next to their son's without Deena's consent. During the interview we went back to this issue a number of times, and Deena's gentle nature conflicted repeatedly with her anger. She would dismiss her feelings ("just have to learn to live with it, I guess"; "I guess it doesn't really matter..."; "I'm just bitter... I shouldn't feel that way"), but return later to a sorrowful and angry questioning of why she was not consulted or considered in the decision. Her repeated pondering of this issue demonstrates how the drive to make sense of events is very strong, and the process continues until acceptable meanings are found or parents resign themselves to meaninglessness. During our follow-up meeting 3 years after the interview, Deena commented that reading her story made her "boil" about this issue again. She seemed to be closer to honouring rather than dismissing her feelings, and was talking more seriously of having her son's grave moved.

### 9.2.2 Andrew's Meanings

Andrew began his story by highlighting his identity as an aboriginal man: "I'm actually from X First Nations Reserve, I'm full blood." For me, the power of Andrew's story lies in his identity as a young aboriginal man with incredible resilience; a young man whose cultural roots provided him with the healing outlet that helped him to emerge from grief as a transformed person. He made a conscious decision to change the direction his life had been taking. He was able to "break the cycle" despite the odds against him in a society where racism against aboriginal peoples has a long and appalling history and persists in the present day, contributing to the tendency of many young aboriginal men, in particular, to take paths of self-destruction.

Andrew's story is abundant with examples of how he found and made meaning from his experience, and the personal transformations he underwent following his daughter's death. His opening words demonstrate his meaning-making process – identifying himself as an aboriginal man from a family who experienced more than their share of perinatal and child losses. It is as though he's saying, "This is who I am, and this is one of the ways I've tried to make sense of why my daughter died." Other instances of his meaning-making and meaning-finding are not about why the death occurred, but have to do with attempting to understand the meaning of life, loss, and suffering.

From the moment he found out his daughter had died, he began searching for meaning. I was surprised by Andrew's tendency, like most *mothers*, to blame himself as part of his search for reasons for his daughter's death. He questioned his role in the baby's death, while also wondering about the role the baby's mother played. In their search for reasons why it happened, the two of them blamed each other and then tried to repair the damage done by the mutual blame, but their relationship was not the same afterwards. As part of his grief and the meaning-making process, his culture gave him the self-forgiveness and permission he needed to accept his past and find peace with thoughts of self-blame.

Part of Andrew's resilience in the face of grief and other life difficulties seemed to stem from his ability to reframe or renegotiate the meaning of events and occurrences from the past that he could not change. For example, not knowing or being able to find out where his daughter was buried appeared to be a source of some painful feelings. But rather than focusing on this issue or his feelings about being denied the information, he shifted the way he viewed it, based on his spiritual connection with his daughter. Since he could not change the situation, the meaning he attributed to it was that knowing where her grave was might change his feeling of spiritual closeness to his daughter. Incidentally, when I gave Andrew a draft of his story nearly 2 years after our interview, he mentioned that he had been contacted by Melissa's mother's family

and was told the grave had been located and he was welcome to visit it. He declined, maintaining his belief that visiting the grave was unnecessary and would spoil his feeling of spiritual closeness to Melissa.

“There is a purpose.” Some bereaved parents are comforted by finding meaning in their child’s death in the form of identifying a purpose, or a meaningful reason beyond the physical reasons for the death. Andrew was one of these parents. Through his culture’s traditional spiritual teachings, he came to believe that there was a purpose for his daughter’s death. Finding meaning in this way did not end Andrew’s grief, but his spiritual understanding of his daughter and the feeling that she died for a reason gave him some comfort and perhaps added to the encouragement he needed to maintain the new direction of his life. He believed such encouragement was necessary because he was not immune to thoughts that would drag him back into the depths of grief and self-destructive behaviour.

Andrew’s self-awareness, his resilience, and his ability to find meaning and spiritual comfort through his culture appeared to be the sustaining qualities that were helping him to resist travelling down the undesired roads when his grief threatened to overtake him. He wondered at his own resilience, unable to fully explain why he is still alive and doing so well with all he’s been through: “I must be, I don’t know, either lucky or crazy or something, or even have a... I don’t know, an abnormal sense of sanity...”

Like other bereaved parents, Andrew struggled with questions of “what would have happened if she had lived?” He wondered if he would he have been mature and responsible, or still involved in alcohol and drugs and in a bad marriage with his daughter’s mother. In essence, the meaning Andrew came to believe was that if his daughter had not died, he might not have turned his life around. Although he would rather have his daughter, he believed that it was his responsibility to learn from his experience and derive as much goodness from it as possible. One of the benefits Andrew created from his experience with grief and suffering was a benefit for others – his desire to use his experiences to be a role model for other young aboriginal people, to help them avoid going down the paths he took. He wanted to show them where he has been, and hoped they might make better choices based what they heard about his experience.

### *9.2.3 Sharon’s Meanings*

Sharon’s birth philosophy and her view of herself as a once disempowered woman are integral parts of her identity. They are meanings that are woven throughout her story in her attempts to make sense of Tasha’s death, her feelings about the birth defects, and the inadequacy and shame that she felt over her body not producing healthy children. The way Sharon described her disempowerment, “shelved” grief, and resurgence of trauma and grief is

reflective of a meaning-making crisis brought about by Tasha's death and the circumstances surrounding it. Birth defects, shame, a troubled marriage, body image, Tasha being dishonoured – all of these issues, and more, were linked in Sharon's complex struggle to make sense of her experience. While telling her story, she noted the interwoven threads of her life that cannot be easily separated, and the centrality of Tasha's death to her life.

Birth Defects: With Sharon's first child having a birth defect, Tasha's birth defects added to the blow to Sharon's self-esteem and her self-image as a physically fit and healthy woman who could produce healthy children. She had accepted the unspoken assumption of our society that if a woman takes care of her body, she will automatically have healthy children. With this assumption shattered, she came to understand herself as being a failure at reproduction, and gave up on her physically active lifestyle since it failed to produce healthy children.

Even after having a healthy third child, Sharon's meanings did not change and she remained very unhappy and disempowered. In what was essentially a crisis of meaning for her, and with many aspects of her grief buried away, Sharon descended into depression and "self-hate." She attributed her depression and "quasi-suicide attempt" to the changed person she had become because of Tasha's birth defects and death, rather than being about the loss as such. In her meaning crisis, she searched for answers for why she was in the situation in which she found herself: "And I'd sit there and I'd watch those [rock videos with a satanic message], thinking maybe I could figure out why this all happened by looking at very satanic things, evil things? Maybe some answers would come about why that all happened."

Sharon's need to talk about and make sense of her feelings, grief, and "shelved" memories was suppressed by her husband's apparent shame over their children's birth defects. His shame and insistence that she tell no one about the birth defects not only stifled her grief and any attempts she might have made to reach out for help, but also perpetuated her own shame over her role in their children's birth defects: "I felt intimidated. And also feeling a sense of shame, thinking, 'I don't know if I want to share that with people.' And so I didn't."

As with any meaning-making endeavour brought about by grief, Sharon's understanding of her feelings over Tasha's birth defects was complex and sometimes contradictory. While recognizing that she felt some shame, she also attributed some of her decisions to not wanting her daughter to be judged, as was the case with not having pictures taken in the hospital. Sharon and I discussed our children's birth defects on a number of occasions, and our joint meaning-making highlighted the contradictory blend of emotions that a parent can feel when a baby with birth defects dies. Sharon contemplated these issues in the hours before Tasha died, as well as over the years since. Whatever shame she felt was essentially inseparable from her

uncertainty about her ability to raise a child with multiple disabilities, and her desire for Tasha not to suffer any longer. The shame Sharon felt over *wanting* Tasha to die while watching her laboured breathing prior to her death was likely an even more difficult meaning to arrive at and admit to because of the dishonouring treatment Tasha received in the nursery (the passive euthanasia). Even though she wanted Tasha to die because life would be very difficult for her, she feared hearing comments that suggested it was best that Tasha died. Such comments, she felt, were like “rubbing it in your face and in your nose... I know that, don’t rub it in... it’s enough that I know it, there’s enough pain knowing that.”

My personal response to Sharon’s discussion of these issues was clearly affected by my feelings about my son’s birth defects. My meaning-making was possibly less complex because my son died before birth, and I was not faced with ambivalent feelings while watching him suffer. However, I have pondered many of the same confused thoughts and emotions of which Sharon spoke. While sharing the meanings we had arrived at, I found myself wanting to convince her not to feel shame over what would have been Tasha’s disabilities if she had lived, even though there were many instances in which she voiced the same passionate opinion that I have about severely disabled persons. It was difficult for me to hear *any* suggestion of shame from Sharon. Instead of respecting her honest acknowledgement of the full spectrum of feelings she had about her daughter’s birth defects, I felt a strong urge to stifle any hints of shame. Perhaps this is because the meaning I arrived at, without realizing it, was that admitting to *any* shame over my son’s birth defects represents a complete rejection of him; a dishonouring of him and his brief life; and the possibility that I would have been ashamed of him, at some level, if he had lived.

Euthanasia: “My baby wasn’t honoured”: Sharon’s struggle to make sense of the trauma she experienced when she discovered Tasha alone and near death in the nursery is evident in the amount of detail she recalled, as well as the uncertainty she displayed when questioning whether she could trust her memories. The thought that hospital staff would engage in passive euthanasia, letting Tasha die cold and alone, was more than Sharon could allow herself to consider. Penelope Ironstone-Catterall, a mother writing about the unexplained death of her 2 year old son, repeatedly used a phrase reminiscent of Sharon’s difficulty comprehending what happened to her daughter: “My memory had, indeed, been overwhelmed by the trauma of finding Isaak’s body, overwhelmed by the reality of *a thought my thought could not tolerate*.” (2004-2005, p. 10, emphasis added) For Sharon, Tasha’s birth defects and impending death were difficult enough to bear, but the added thought that she was left alone to die was more than Sharon’s thoughts and emotions could tolerate at the time, and for many years afterwards.

Sharon's "shelving" of the euthanasia memories likely occurred because such a practice was unfathomable to her, even once she accepted her perception as being true.

Sharon tried to make sense of the medical system that allowed her baby to be treated this way. After her experience with her son's surgery and hospital stay, Sharon had a feeling of trust that hospital staff would take care of Tasha in the same way when she needed to leave the nursery to rest. The fact that her trust was unfounded and her daughter was left to suffer and die alone therefore reinforced even more the perception that they did not value her daughter's life because of her birth defects. Essentially, she came to the meaning that her daughter was viewed by others as too deformed to be worthy of life. This message continued to be relayed to her in encounters she had after Tasha's death within both the medical system and her social circle.

Despite her relative certainty that the hospital was practicing passive euthanasia with Tasha, she refrained from discussing her suspicions with anyone for fear of being told, "Yeah, but your baby was going to die anyway. So why would you want to prolong the struggle and suffering of your child?' Almost as if *I'm* not justified to be *angry* that that happened... what it does, is it dishonours her, and devalues her life."

"I feel I abandoned her": The traumatic memory of finding Tasha alone and near death in the NICU nursery is forever imprinted in Sharon's mind. She arrived at the guilt-laden meaning that she abandoned her daughter to that situation, "to go and get a few hours of sleep and something to eat." This was her explanation for why she did not feel a spiritual connection to her daughter, an explanation that carried the implication that Tasha was angry with her mother for not staying by her side to protect her. Sharon spoke of wanting to work out this issue with her baby daughter, so that she can "feel a sense of communication" with Tasha that she longed for but never experienced. While the implication is that she wanted *Tasha's* forgiveness, likely what needed to be worked out was her own *self*-forgiveness.

While not explicitly making the connection to this feeling of having abandoned Tasha, other parts of Sharon's storied meaning-making emphasized how being in the medical system caused her baby to suffer needlessly, and caused her to be separated from Tasha even though she never wanted to be. For example, she talked about specifying in her birth plan that she did not want to be separated from her baby if she needed to be transported, and that she did not want silver nitrate to be put in the baby's eyes. Neither specification was followed through on, nullifying her efforts to protect Tasha in these ways. Once she became aware of Tasha's prognosis, she did not want to leave her baby's side, but was unable to do so because of her need for a rest. Her decision to entrust her daughter's care to the nurses ultimately resulted in



the feeling that she had abandoned her daughter. These instances of Sharon being the best mother she could be under the circumstances contained a common thread of meaning – as though she was trying to convince herself that she tried to protect Tasha but failed for reasons beyond her control.

Re-Experiencing Grief and Being Nurtured: For many years, Sharon had an unfulfilled need to grieve and be nurtured, to have the significance of what happened to her and Tasha understood by others. This acknowledgement was absent not only from others, but from herself as well. The meaning she ascribed to her experience for many years was that it was not “a big thing” that should affect her life.

The resurgence of her grief, memories, and trauma that she experienced when she made contact with other bereaved mothers was extremely confusing and frightening for her. The posttraumatic stress symptoms that she experienced made her initially question her sanity and the authenticity of her feelings (“Are you creating this?”). In trying to explain the resurgence of memories and grief, Sharon wondered why it happened when it did, rather than earlier in her life. She speculated that she had “grown and matured as a person” over the years, and she was not strong enough to process her experience sooner because of the state of her self-esteem after Tasha’s death and the impact of having two children with birth defects. Sharon’s final birth experience helped to pave the way for improved self-esteem and the strength to relive her memories, trauma, and grief. Likely, too, the acknowledgement and nurturance she received from the fellow bereaved mothers she contacted provided the caring context that she had needed and unconsciously craved over the years since Tasha’s death. Once this context was in place, she was free to re-experience and make sense of her experience in a way that she had never done before. Over a relatively short period, she began to feel healthier and more empowered. It was as though the processing of her memories and arriving at new meanings through telling her story in a safe context was necessary before she could feel like a whole person.

#### *9.2.4 Judi’s Meanings*

Judi’s story is a surreal one with a harsh and bitter edge, a tragedy filled with unrelenting grief, anger, shame, and self-blame. Beneath the anger and bitterness is an emotionally vulnerable woman with a caring nature, a childless mother with unfulfilled needs to nurture and to be emotionally nurtured herself. The experience of her son’s death shaped the person Judi has become. It was the focal point of her life and the way she came to view herself and the world around her.

“The worst thing that could happen to anybody”: Losing a child is generally viewed as the most significant loss that a human being must bear. For Judi, the added injustice of the circumstances surrounding her son’s death led her to view her loss as the most significant loss that could have happened to her or to anyone else. She perceived her loss to be worse than any other, including the loss of an older child or a happily married couple losing a baby (because they could share their grief). Judi’s comparison of herself to other bereaved parents in this way is a good indication of the lasting impact her experience had on her life. This is the overarching meaning she has made of her experience – that it is the worst possible thing that could have happened and she has suffered from it ever since. She felt that her son’s death magnified life hardships that began when she was a child, and her grief intensified and contributed to those hardships that occurred since.

Adding to Judi’s sense of this being the worst possible loss was her permanent status as a childless mother. She speculated that her grief might have been easier to bear, despite the magnitude of her loss, if she had been able to have another child. She is left learning how to live with the reality that she will never have a child to raise. Judi’s inner turmoil over being a childless mother is reminiscent of Talbot’s (2002) comments about her struggle with this issue several years after her daughter’s death (note that the complexity of Judi’s struggle to come to terms with her lost motherhood is perhaps even greater because of having only “mothered” her son for 9 hours):

...When no one calls you mother anymore, what do you do with the part of you that has learned how to be and loved being a mother? ...this was the missing piece, the reason my soul felt like it was dying... the need to confront the loss of my parenting role as a separate loss... I felt I had made peace with Leah’s death in many ways and that that process would be ongoing for the rest of my life... I knew I would always miss her terribly, and that we would always be connected by love, which never dies. But I was still struggling with the loss of my parenting self. (Talbot, 2002, p. xxix)

“Who can understand it?”: Although longing for emotional support and understanding, Judi did not believe there was anyone who could understand. The harshness of the judgement Judi anticipated receiving if she were to seek support for her grief was formidable. Essentially, she expected people to think something such as, “It’s your fault, because number 1, you were an unwed mother, and number 2, how could you not know you were pregnant?! If you had been taking care of yourself the way a proper, married mother-to-be would, your son wouldn’t have died.” Whether her expectations were exaggerated or based on reality, the shame Judi believed society placed on her because she was a single mother had a great impact on her willingness to seek support. She resisted the stigma, saying that she was not ashamed, but she remained

painfully aware of it: “I was one of “*Those*” girls. I was a *dirty little girl*, I was an unwed mom! And not only that, I killed my baby! ...Like, I was a whore, plus.. a murdering whore!”

The belief that others cannot understand her experience and would judge and blame her explains Judi’s reluctance to reveal her vulnerability and share her experience with anyone. She recognized the “brazen” mask she wore to hide the pain she felt inside, an attempt to avoid judgement and maintain her mental stability. Hiding pain and vulnerability by not sharing one’s story seems to be a common self-protective reaction of perinatally bereaved parents. Such self-protection seems necessary in a society that has been prone to ignore these types of losses, and to push “getting over it” with respect to loss in general. The motivation behind Judi’s emotional independence was similarly self-protective, intended to prevent her from being hurt any further. Judi took this to the extreme, however, believing there was *no one* who could remotely understand what she has gone through because of the unusual circumstances of her pregnancy. She appeared to think that not even a fellow-bereaved parent who had a perinatal loss would understand. Yet, she did take the opportunity, and the risk, to speak to me with complete honesty and openness to self-exploration.

The price of masking her pain and keeping “it all buried inside” was a feeling of emotional isolation. Judi held a mix of meanings, feeling that she could depend on and trust only herself while also feeling “abandoned by everybody” and craving a connection with someone who could understand and share her grief. Ironically, masking her pain in an effort to be “strong” left her to cope alone (which was likely *more* detrimental to her mental health), since others may have perceived her independent and strong demeanour as an indication that she did not need support. Further adding to her isolation in her grief was the death of her fiancé shortly after her son’s death, as well as the belief that she should not burden her parents by talking with them about her grief. Judi’s search for meaning was consequently made more problematic by not having others to help her ponder the meaning of her experience: “I couldn’t *share* my grief with anybody. I couldn’t sit down and say.. was *I.. really.. responsible?* You know, like, *tell* me. How.. was, was I *really* at fault? You know, was.. did I *kill my own son?*”

It is possible that in addition to self-protection, Judi’s choice not to seek out emotional support was a form of self-*punishment*, punishment for her self-alleged role in C-J’s death. She commented that, “I think I *torture* myself,” by not forgiving herself for her son’s death. In addition to no *self-forgiveness*, perhaps she believed that she did not deserve support and compassion from *others* as well. While it is possible that individuals in Judi’s social circle would have judged her in the way she expected, it seems that the greatest judgement was from within. Shame

prevented Judi from allowing herself to be heard and given compassion, and shame was the underlying feeling that she was unable to release<sup>17</sup>.

“The blame”: Judi has viewed her life since C-J’s death through the lens that she took on in trying to make sense of his death, the “I failed as a mom.. I killed my son” lens. Her self-blame, combined with her childless mother status, has left her in a perpetual state of grief. The intensity and longevity of her rage at the doctor involved has also undoubtedly made it even more difficult for her to find peace with her loss. Judi recognized that she had not made sense of her experience, but was stuck in anger and blame. She acknowledged the irrationality of her self-blame, yet she could not find a way to release herself from it. She believed that she could only forgive herself if she could first forgive the doctor, which she maintained would never happen unless he came to her and asked forgiveness. With that being an extremely remote possibility, she was left with the belief that the self-blame for her son’s death will never subside.

Many parents who lose a baby blame themselves for the death in some way, at least for a short time during their most intense grief. Judi’s self-blame arose primarily from the added layer of shock that came with not knowing she was pregnant until she went into labour, and the associated belief that her strict diet contributed to her son’s death. Judi was engaged in a life-long struggle to come to terms with the surreal set of circumstances that led up to C-J’s death. Clearly, her ability to make sense of her experience became much more difficult because of these unusual circumstances. The trauma and senselessness of what occurred, layered on top of the loss itself, continued to affect her in her daily life in terms of second-guessing all of her decisions and being overly conscious of new bodily symptoms.

Judi spoke of her son’s spirit being with her, but in a punishing way – to remind her that she failed, that she killed him, and that she must not fail ever again, at anything. She feels an intense, compulsive need to check on his grave, to take care of it and make sure no further vandalism is done to it. Thinking of him every day, “almost every minute” also appeared to be more punishing than comforting to her. She certainly had an ongoing relationship with her son, but it was one involving pain and punishment rather than comfort and peace.

Impact of Judi’s Meanings on her Grief: The detrimental effects of Judi’s childless mother status, seething anger at the doctor, and the core meanings she ascribed to her experience

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<sup>17</sup> Judi’s self-blame and underlying feelings of shame are reminiscent of how Kagan (Klein) (1998), a psychotherapist and grief theorist, spoke of shame in reference to her daughter’s accidental death at the age of 11. She described shame as being a “painful sense of guilt and of unworthiness... one of the most overwhelming emotions in parental grief... *shame* is a fundamental fear of condemnation by others for failing to protect your loved ones – for failing to fulfill your social role as a parent. Shame causes a decrease in self-esteem... and lack of feelings of self-worth.” (p. 107)

(self-blame, feeling no one could understand) could be seen in every facet of her life, including relationships and her overall health and mental health. She seemed unable to move from searching for reasons/placing blame for the death to searching for positive meanings in her baby's life and new meaning and purpose in her own life that did not involve fulfilling her need to nurture.

Given the level of grief and anger and self-blame Judi has had for so many years, I found it amazing that she has continued to function as well as she has. Perhaps she has survived this long, suicide attempts and all, because she has some protective, resilient characteristics despite her description of herself as being potentially quite unstable. Her assertiveness and determination was obvious in many instances in her story (e.g., she “demanded” her son be christened; she stood by his side, for 9 hours, until he died; she insisted on having a private room rather than staying in the maternity ward; she has dealt with her grief alone, which has been detrimental, but she has managed to survive). Despite the incessant self-blame, Judi's desire to forgive and to heal was apparent, and she displayed glimmers of hope that telling her story would be the beginning of releasing herself from the damaging meanings she has held for so many years.

#### *9.2.5 Stacie & Dan's Meanings*

Identifying meaning-making in Dan and Stacie's story was a very different exercise than for the other four stories in this project. Most of the meanings evident in their story were reached as a couple, or were reflected in discussions of the family meaning-making that their families engaged in. If Dan and Stacie had been interviewed separately, it is possible that additional personal meanings would have emerged. Yet it seems that the power of their story, their relationship, and the supportive social network that has encircled them in their grief might not have been as evident within individual interviews.

Family Meanings: “Everyone's blaming themselves”: Stacie and Dan's story revealed that not only parents blame themselves for the death of a baby; in their case, other family members engaged in self-blame as well, including both of their fathers. The meaning-making process that led family members to such conclusions was varied, with the rationale sometimes being hereditary, other times spiritual. Stacie was struck by how they and their families initially hid such individually arrived-at meanings. Although Stacie and Dan did not go into detail about how they and their families came to terms with these feelings of responsibility for Reanne's death, the way they spoke of their families and close friends suggested that coming to terms with self-blame was a collective effort. The feelings were processed *as a family*, and became part of the family's overall storied meanings for making sense of Reanne's death.

Family Meanings: “She brought us all to our knees”: The family grief that ensued after Reanne’s death was perhaps greater than anyone could have anticipated. Dan spoke of the incredible power of grief over one who had been in the world such a short time. Stacie’s father, too, commented on the intense grief of the men of the family over a tiny baby girl who lived less than a day. Dan noted the shock and difficulty he had seeing his own father’s grief over Reanne. The meaning Dan seemed to derive from witnessing his father’s grief was that even a self-made, successful, “strong” man who could resist a family history of alcoholism and withstand various physical traumas was broken by this immense loss. Perhaps it also gave Dan the permission he needed to grieve openly without shame.

Although difficult to watch the family’s grief, it seems that this collective meaning, that Reanne was so important to the family that she “brought us all to our knees,” would also provide comfort and solace in knowing that she was a valued member of the family. In other families, as some of the other participants in this study indicated, their grief over their deceased babies was not only dismissed by society at large, but by close family members and friends as well. Despite all of the trauma and grief that Stacie and Dan experienced, it seemed that they felt very supported by both friends and family, perhaps to some degree because of family meanings such as this.

Family Meanings: “The little girl”: Stacie conveyed what was a difficult but honest meaning for them and their families to admit, that having the girl from the set of twins die initially added to their grief and sense of injustice in the loss. Having a girl in the family appeared to be important to everyone. Stacie’s father wanted a granddaughter and felt responsible for her death because of it. Dan’s comments reflected the special relationship he looked forward to having with a daughter, and the sense of injustice he felt in losing her before he had a chance to be a father to her. Stacie wanted to try to have another baby after awhile, but came to the realization that what she wanted was a *girl* and *only* a girl, and perhaps would be trying to replace Reanne if they succeeded in having a girl. This meaningful and honest insight helped her to see that having another child was not in the best interests of anyone, especially the child, and she was able to accept quite peacefully that they should not have more children.

Dan’s and Stacie’s Personal Meanings: The trauma that Dan experienced as a result of all of the circumstances surrounding Reanne’s death added to and perhaps determined what his long-term grief was like. Throughout the interview, he returned a number of times to describe the “pure hell” that he experienced the day that Reanne died. The numerous stresses that he needed to contend with *in addition to* her death seemed to work together to leave him somewhat traumatized, in addition to grief-stricken. From the moment of the twins’ birth and Stacie’s lungs

collapsing, he found himself in a world that was suddenly chaotic and out of control, and he was powerless to change what was happening. He described it as “probably the *wors-st day*.. I will ever have in my entire life. You know, I can’t think of anything that’s going to be worse. Unless of course.. something was to happen to one of my boys, now.”

In Stacie’s case, in addition to the survivor’s guilt she felt and her longing to have a daughter, another central personal meaning that she discussed was her belief that she would not have survived her grief if she had lost both of the twins. She spoke of Aaron as her “miracle,” which affected how they viewed and treated him as a baby and toddler.

Couple Meanings: “A double whammy”: With their loss being one child from a set of twins, Stacie and Dan were faced with an additional layer of complexity to their grief that they needed to make sense of. As Stacie put it, their loss involved “not only being robbed of a child, but being robbed of the special feeling people with twins get.” The “double whammy” that they experienced – the joy over a son who grew stronger each day, and the grief over their greatly anticipated daughter – presented them with a number of issues to be contemplated and made sense of. With Aaron being in the hospital’s NICU for several months, they felt they had to squelch their anger at the doctors. Stacie commented that it was also difficult for them to understand “what was so wrong with Reanne?,” given how “perfect” Aaron was. Dan voiced their doubt that the doctors made the right treatment decisions with Reanne when he said, “they did everything.. *apparently*, they possibly could.” Ultimately, they came to the meaning that through the babies’ profound twin connection, Reanne “gave her life for Aaron” so that Aaron could be saved from a life-threatening infection.

Couple Meanings: “A part of the family unit”: Dan and Stacie had a feeling of an ongoing relationship with Reanne, one that they encouraged openly with their boys: “...she is a part of the *family unit*. She’ll be in my family ring, she’s.. Aaron’s twin, Brendan’s sister, they both know that.” Although the family did not talk about Reanne on a daily basis, they were open and accepting of Reanne’s name being mentioned in conversation. The spiritual sense that they have of Reanne was felt by their sons as well, with Brendan making comments such as, “I wonder what Reanne’s doing right now,” which the family welcomed as an appropriate way of keeping Reanne a part of the family. Dan spoke of Reanne being a “guardian angel” for the family. He believed that Reanne was watching over other family members, including saving his parents from what could have been a fatal accident. He also credited Reanne with his survival during his separation from Stacie.

Couple Meanings: Thoughts on Grief: When I asked Stacie and Dan their opinion on the theoretical debate of whether grief has an endpoint or if a person ever “gets over it,” they spoke



passionately about thoughts they appeared to have contemplated before. Their passionate response seemed to stem from how they felt about the information on grief that was given to them in the hospital after Reanne died. In particular, they took exception to the grief pamphlets that the hospital used that followed a stage-model of grief, suggesting an endpoint to the various emotions of grief and making little acknowledgement of the unique hurdles of a perinatal loss. It seemed that Dan and Stacie initially accepted what the pamphlets described, “as if it’s like the written word,” but later realized that what they were experiencing had little similarity to the rigid sequence of emotions that they understood the pamphlets to be suggesting. In the midst of their early, raw grief, it is possible that the discrepancy between how they felt and how they believed they should be grieving based on the pamphlets made their search for meaning even more difficult. A grieving parent can be left wondering, “what’s wrong with me?”, as Stacie expressed.

The alternative understanding of perinatal loss and long-term grief that Dan and Stacie came to accounted for the resurgences of grief they had years later in response to countless triggers. Dan commented that six years later he continued to think of Reanne numerous times a day. Both agreed how “very unnatural” it is for parents to outlive their children, and that it does not fit with the way the world is supposed to work. Stacie highlighted the unnatural and unexpected nature of a perinatal loss when speaking of why the grief stages that were presented to them were so dissonant with their experience. The meaning she reached in trying to understand perinatal loss is that it is a “mentally disturbing” event because it is out of sync with the natural order of life events. As she said, “It’s.. more *damaging*.. than I think people actually think it is... Like you’re trying to.. figure out, like this is supposed be the *start* of my life, not the *ending* of~” Despite the ongoing pain of the unnaturalness of losing their baby daughter, they noted that with time, they were able to think of Reanne with joy and happiness instead of only sorrow.

### 9.3 Common Threads of Meaning

The purpose of the above discussion of the uniqueness of personal meanings within parents’ stories was to achieve a depth of understanding of meaning-making following a perinatal loss that preserved each parents’ individuality. Focusing on these 5 individuals’ meanings demonstrates the varied and complex themes and meanings that they gave to their experiences, some of which could be said to be common or universal, but as a whole, are dependent on and specific to the individuals’ unique histories, personalities, and circumstances. On the other hand, valuable complementary information can also be gleaned about the experience of perinatal loss and the relationship between meaning-making and grief by considering meaning-making themes that are common across individuals’ stories.

The following discussion is organized into two sections: common meaning-making influences, and common meaning-making strategies. The intent of this discussion is to shed a brighter light on previous understandings of *how* parents reconstruct meaning following a perinatal loss, and how (and what) meaning-making influences affect their grief process; it is not intended to be a comprehensive thematic analysis. As such, I chose to focus on only those meaning-making influences and strategies that were particularly salient in the majority of parents' stories. This discussion also provides an opportunity to hear from 9 additional participants<sup>18</sup>, representing another 6 families (see Table 2), whom I interviewed but whose complete stories could not be included for the purposes of this project<sup>19</sup>. Their experiences and words of wisdom add further important insights into long-term grief and meaning-making following a perinatal loss.

Table 2: The participants.

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Christine and Bill: I interviewed Christine and Bill in separate one-on-one interviews, which they chose over being interviewed together. They were in their early 40s when their second baby, Abigail, died 4 months before our interview. She died during a complicated labour and was delivered by an emergency C-section. Christine sustained damage to her bladder during the surgery, which was not detected until several weeks later and required that she be catheterized and later hospitalized again. Bill and Christine believed the doctor was negligent in monitoring the progress of labour and in various decisions that were made, and that this negligence led to their daughter's death. An investigation through the College of Physicians and Surgeons was pending. They have an older daughter, Dawn, who was 18 months old at the time of the interview. When Christine contacted me about the study I indicated to her that I was focusing on parents whose losses occurred at least a year before, but she decided she would like to meet anyway, and offer whatever help she could with the project. In the time since the interview, they have been told they cannot have any more children.

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Katrina and Luke: Seven months before our interview, Katrina and Luke lost their baby girl, Brittany, when she died before birth for reasons that were not yet known at the time of the interview. Like Christine and Bill, Katrina and Luke decided they would like to participate in the study to offer whatever help they could, despite the short time since their loss. They, too, launched an investigation into what they viewed as incompetence on the part of their doctor which led to inadequate monitoring in the final month of a high-risk pregnancy. They were in their late 30s at the time of the interview, and had an older daughter, Brandi, who was 3 years old. Since the interview, they have had twin boys. All of Katrina's pregnancies came about through in vitro fertilization.

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<sup>18</sup> Note that there is a 10th additional participant when counting Irene, who was introduced and whose story was touched on in Judi's story (chapter 7). Portions of Irene's story are also included in this chapter.

<sup>19</sup> I am in the planning stages of publishing this dissertation as a book, with all 12 narratives included in full.

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Mona: Approximately 14 months before our interview, Mona and her husband were in their late 20s when they lost their second baby, Hannah, when she was born prematurely at nearly 26 weeks gestation. At 20 weeks gestation, Mona had experienced a tearing away of her membranes, resulting in haemorrhaging and a massive loss of amniotic fluid. Hannah had survived for 6 weeks in the womb with very little fluid, and she was born alive. Attempts were initially made to keep her alive because she was at the cut-off mark for the weight and gestational age at which hospitals will intervene, but Mona and her husband decided to stop the efforts because of Hannah's suffering. Mona's story is particularly unique because of their decision to take Hannah's body home with them and have a family-planned burial the next day, to avoid having to leave her body in the morgue. Their older daughter, Jasmine, was 2 years old at the time of Hannah's death. After Hannah's death, they experienced an 11 week miscarriage. Since the interview, they have had another baby girl.

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Sonya and Owen: Nearly 2 years before our interview, Sonya and Owen were in their late 30s when they experienced the death of their first child, Alanna, who was stillborn following a full-term pregnancy. Sonya had gone into labour naturally, and it was not determined that Alanna's heart had stopped beating until Sonya went to her doctor's office during the early stages of labour, and was sent for a non-stress test. The cause of death was a severe heart defect. Owen and Sonya found the treatment they received was inconsistent; they said that when they learned that Alanna was dead, the doctor involved and other staff members were either extremely insensitive or rather disorganized and confused as to how to proceed. In contrast, Sonya and Owen felt their own doctor and the labour and delivery nurses were very compassionate and well trained to deal with this type of loss. Following Alanna's death, Sonya had an early miscarriage. At the time of the interview, she was in her third trimester with another pregnancy, and they had a baby boy later that spring.

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Penny: Over a period of 5 years in the 1970s, Penny experienced the death of three baby girls following two twin pregnancies. After the birth of her first child, her second pregnancy in 1971 ended with the neonatal death of twin girls, Marie and Theresa. She subsequently had 2 more children, and again became pregnant with twins in 1976. She was hospitalized for the final three months of her pregnancy, and experienced insensitive and incompetent medical care and treatment decisions which she feels led to the death of one of the twin girls. Around the time of her due date she gave birth to her babies; the first was a healthy baby girl, and the second, Jane, had died quite some time before birth. Penny did not see any of her three daughters who died, and a priest and a nun named them. She had been divorced for 6 years at the time of our interview.

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Rachel: Rachel was in her early 30s when her second child, Gregory, was stillborn shortly before his due date in 1977. Rachel had noticed reduced movements and went to see her doctor, who couldn't locate the heartbeat because of "swishing," but said that likely the baby was fine but just too large to move around much at that stage of the pregnancy. She went into labour naturally a couple of days later, and 2 hours before Gregory was born hospital staff confirmed his death. There was no obvious cause of death upon autopsy, other than a very tightly twisted umbilical cord. A nurse who had training as a midwife delivered the baby, and she recommended that Rachel not see her son because of skin deterioration from being dead for a few days. Rachel had no regrets, preferring to remember her son as she had imagined him in her mind, "as any

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other cute cuddly pink baby.” She had another baby boy around a year after Gregory’s death. Rachel’s story was unique in that, aside from Andrew (Chapter 5), she was the only other participant who had no complaints about medical staff or support that she later received from friends and family. She had a supportive and kind husband, a neighbour who was a good listener, and she found solace in her Christian beliefs. Her husband died 3 years before our interview.

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Deena: See chapter 4.

Judi: See chapter 7.

Andrew: See chapter 5.

Irene: See chapter 7 (end).

Sharon: See chapter 6.

Dan and Stacie: See chapter 8.

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### *9.3.1 Common Meaning-Making Influences*

The uniquely individual meaning-making process of each of the parents I interviewed was both informed by and contained within the broader social and cultural context in which they lived their lives. The social and cultural belief systems, customs, and ideologies about loss and grief necessarily influenced these parents in their attempts to make sense of their losses and experiences of grief. When I began my interpretation of the stories using the voice-centered relational approach to reading the transcripts, I chose to include a reading which focused on social and cultural “voices,” because I assumed such voices would be relevant and present to some degree. I looked for instances of social and cultural ideologies, structures, and contexts that appeared to impinge on, constrain, enable, or empower the parents in their ability to make sense of their experiences (Mauthner & Doucet, 1998). While finding such influences on parents’ meaning-making was to be expected, it was striking how universal, prevalent, and central these social and cultural influences were in all of the parents’ stories.

What the social and cultural voices in the stories expressed was that even with absolute support and compassion from others, the grief and trauma of the babies’ deaths was difficult to endure. But with questions about the medical circumstances surrounding their babies’ deaths; unrealistic expectations imposed on the parents regarding the intensity and duration of their grief; little or no acknowledgment for their losses and a lack of emotional and other support; and cruel or insensitive comments that disenfranchised their losses, grief and the ability to make sense of their experiences was made exponentially more difficult. In the sections that follow, I focus on two social/cultural realms that were most prominent in each of the 12 individuals’ or couples’ stories: encounters with the medical establishment, and responses of their social networks.

### *9.3.1.1 Encounters with the Medical Establishment*

As the first social institution that parents encountered at the time of their losses, the medical establishment held a powerful potential for influencing the trajectory of parents' meaning-making attempts and their grief. Although not necessarily a part of our daily lives, the healthcare system is an influential social institution that plays a central role in the lives of Canadians, not just in terms of illness and injury, but also in the beginning and ending of lives. With the surreal juxtaposition of birth and death that perinatal loss represents, the healthcare system is involved automatically and intimately. As the parents' stories revealed, this involvement sometimes facilitated and other times stifled or compounded their grief. With improved understanding and policies for dealing with perinatal loss in recent decades, the period in which the losses occurred determined which influence the medical establishment had to some degree. The parents with the most recent losses, however, spoke to the continuing potential for interaction with the healthcare system to complicate meaning-making and exacerbate grief after a perinatal loss.

#### *9.3.1.1.1 Authoritarian and Paternalistic Ideology*

When medical care shifted from the home to the hospital early in the 20<sup>th</sup> century, the institutional nature of hospitals made it inevitable that patients would lose some of their autonomy, dignity, and rights to make decisions about their care. Historically, the treatment ideology adopted within hospitals denied the authority of parents in decision making that might have helped them in their grief (e.g., being informed of what was wrong with the baby; being involved in treatment decisions; being with the baby in death; seeing and naming the baby after death; making decisions about burial and baptism). This authoritarian ideology was apparent in all procedures, both before and after the death<sup>20</sup>. For example, Sharon's experience demonstrated this mindset during her labour, when her nurse appeared angry about her refusal of unnecessary but traditional procedures or medications. Penny, who was on bed rest for 3 months with her second set of twins, also experienced the authoritarian attitude of the medical establishment in terms of prenatal care in general:

I was hospitalized 'till I had Cora.. so I was separated from my other 3 kids for 3 months... I started off in [the first] hospital.. and.. {sigh} it was very hard there, because they had this rule... that only the husband could come and visit, I couldn't get any other visitors. And they wouldn't change the rules. I'm going, "Well I'm here because I can't go home." And the nurse would say, "No, we can't, we can't break the rules." I said, "Can't you have my mother or my sister or somebody come and visit me?" "No, no, we can't break the rules."

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<sup>20</sup> It should be acknowledged that this ideology likely extended to all aspects of hospital care for any type of illness or injury, rather than being unique to perinatal care or perinatal losses.

Parents whose losses occurred before approximately 1980 experienced the greatest degree of disregard for their preferences, opinions, and dignity. Penny's experience occurred at a time when patients' consent for having their treatment included as part of the training of doctors and nurses in teaching hospitals was not obtained. In Penny's situation, she was subjected to being observed by a multitude of medical staff and students during the delivery of her twins, without consideration of her preferences. Penny's story also contained examples of the indignities that patients were sometimes subjected to (dependent, of course, on the individual professional):

And so this [resident] doctor would get me, and then he would take that ah.. that cream there [for the Doppler device], and I'll never forget that, because he's dotting it up [on my abdomen], he says, "Oh, my goodness," he says, "you look like a birthday cake." You know, just little remarks like that, it was very embarrassing...

As an interesting cultural comparison, Irene's experience in England in the mid 1960s was very similar to that of the mothers in Canada<sup>21</sup>. As with Deena and Penny, the hospital staff involved in Irene's care made the decision to baptize her baby without considering that they should seek her permission first. Although these women were glad that their babies were baptized, the point here is that at the time that they had their babies, patients were not consulted or allowed to make their own decisions. Again, having decisions made for them extended to all aspects of their care, not just in terms of their babies' deaths. Irene described the authoritarian stance of hospital staff when she had her subsequent child after her loss, and the assertiveness required of her and her mother in challenging that authority. In one case, hospital staff were "very forceful" while insisting that only husbands had visitation rights, and did not relent until Irene's mother asserted herself angrily. As well, the same hospital staff wanted to force Irene to breastfeed, and an intense argument took place before they would abide by her choice to not breastfeed.

As another example of the historic paternalism of the medical profession, both Penny and Deena told of how their concerns were patronizingly dismissed by their doctors, only to be later found to be accurate. In Deena's case, she voiced her concerns about her son's condition but was told that the bruising, which was later found to be a result of haemorrhaging, was normal. Penny was similarly dismissed when she told her doctor about her suspicions that she was pregnant with twins:

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<sup>21</sup> Irene's experience was similar aside from the option of midwives in England, whom she experienced as being more compassionate during labour and delivery than the nurses and doctors in the medical system.



And, everybody, even the health nurses would say, “You look like you’re having triplets, you’re so huge.” And I remember going to doctor.. and telling him, “I’m too big, there’s something wrong.” And I remember him just patting my belly and going, “Oh, no, no, you’re fine, you’re fine.” ...so by the time he came in, when he came he examined me, and then my water broke. And ah, but still, he didn’t tell me I was expecting twins. He knew at that point but he didn’t tell me.

These “doctor knows best” kinds of responses may have been based as well on the view still prevalent in that era of women being intellectually inferior to men and emotionally fragile. Thus, any concerns they had were attributed to “nerves” rather than acknowledging the women’s intuitive knowledge about their own bodies. For example, Judi’s doctor repeatedly attributed her pregnancy symptoms to stress and a “mental problem.”

For the perinatal deaths that occurred prior to the 1980s, decisions made by hospital staff were often based on the intention to protect the parents from unnecessary pain, but they ignored the healing potential of fully informing and involving the parents<sup>22</sup>. The medical staff involved in Deena’s experience demonstrated this philosophy when they realized her son was ill but did not inform her of why they were taking him from her. It is interesting to note the authority implicit in the phrasing Deena used: “They came and *they said I couldn’t have him! They would feed him for themselves... they didn’t tell me why...* [once they told her that he would not survive, several hours later] *they let me go and see him*” (emphasis added). Penny’s experience with her first set of twins also illustrated what was likely the protective efforts of staff and clergy to minimize the bonding of mother with baby, which they assumed would occur if they allowed unlimited contact and involvement in naming and burial decisions (Phipps, 1981):

So ah.. I think.. [the twins] lived for about 2 hours... so I just ah.. briefly seen them. And then.. went to my room. And then after that ah, they came and told me that they were dead. So I didn’t even.. you know, in those days, I didn’t even get to hold them.. or see them. So then ah.. the priest came, and he’s the one that, you know, they buried them, while I was in the hospital {voice breaking, crying}.. and ah... and he’s the one that named them, for me.

When her third baby died 5 years later, Penny’s preference to not be sedated was ignored, which again was likely based in part on a desire to minimize her emotional pain. She was also not allowed to see her baby (likely because of the belief that she would become overly upset by viewing the macerated condition of a stillborn baby; see Phipps, 1981), and was again not

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<sup>22</sup> This healing potential can be seen in the following comments made by two of the fathers: “I thought it would really bother me holding our dead little girl, but it.. felt good. Even though it was so bad. I was dreading when she was.. delivered.” (Luke); “The work on the coffin was important. If I hadn’t done it, ah, I’m afraid I might have gone into a wallowing. And that wouldn’t have been all that productive. And I think



consulted in the naming or burial arrangements. Sharon also experienced this protective mentality before her daughter's death, when her doctor delayed fully informing her about her baby's prognosis. Sharon experienced this as another disempowering action that denied her the ability to make fully informed decisions.

These examples of the authoritarian and paternalistic philosophy and actions of the medical establishment in earlier decades are a striking contrast to Mona's experience of the changed ideology of the medical system 15-30 years later. When she experienced a tearing away of her amniotic membranes and a massive loss of amniotic fluid at 20 weeks gestation, she and her husband were treated with the utmost compassion and respect, and were fully informed and included in the difficult decision-making about whether to continue with the pregnancy. Mona's hospital experience after her daughter's death also demonstrated the impressive degree to which the healthcare system had changed by 2001. She and her husband were allowed to hold their daughter as she died; their families joined them in the hospital and spent most of the day "getting to know" their baby, Hannah; and the nurses and doctors involved in their care were sensitive and compassionate. What was most striking was the way the hospital handled the burial decisions. Mona was deeply troubled by the thought of her baby being sent to the morgue to await burial. In discussions with her nurse, she and her husband, Trent, made the decision to take their daughter's body home with them from the hospital:

...after talking to Trent about it, and after my nurse talking to Trent about it and saying, "*It's okay*. If this is what you want to do, yes, you can." You know, "Yes, many years ago we didn't. Didn't allow that at all. We didn't allow *anything* that's been going on today. But whatever you want is what we'll do, because... it's what you need. You know, and, and whatever you feel is best."

Not all of the parents with more recent losses had as good an experience with the healthcare system as Mona did, however. Even in the changed atmosphere of the past 5 to 10 years, the authority of the hospital came before parents' decision-making rights. For example, the way that hospital staff informed Stacie of her daughter's death was experienced by Dan and Stacie as being authoritarian and insensitive, as well as endangering to Stacie's life (i.e., telling Stacie while she was alone in ICU, rather than waiting for Dan to be present and give her the news himself). While perhaps meant to be a helpful part of Stacie's care, these interactions served only to create further distress for Dan and Stacie at an already traumatic time.

#### *9.3.1.1.2 Questions about Medical Policies, Practices, and Competence*

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there would have been a.. downward spiral.... 'Cause when there's nothing positive to focus on, there's only one way to go. At least that's what I noticed." (Bill)

A prevalent concern voiced by several of the parents, including those with losses that were more recent, was the issue of medical competence. Concerns about human error and incompetent medical professionals focussed on either specific medical personnel, or the hospital as a whole. In all cases, the alleged incompetence significantly complicated the parents' meaning-making and grief over their babies' deaths. For example, Judi's doctor attributed her pregnancy symptoms to stress and prescribed Valium to her without running any tests to rule out other possible diagnoses, despite Judi voicing her concern about her symptoms continuing after her initial visit to his office. Judi's anger at the doctor and her self-blame were palpable, 26 years later. Luke and Katrina had an obstetrician who came very highly recommended when they were expecting their second baby, conceived through in vitro fertilization (IVF). They felt that the doctor treated it as a high-risk pregnancy until the final month, and then neglected to keep careful track of the results of precautionary tests and ultrasounds. In particular, a final ultrasound done shortly before the baby's death indicated that the baby should be monitored more closely, but Katrina and Luke were not aware of this result until after the fact. Luke felt guilty for trusting the doctor rather than listening to Katrina's concerns, and both were still angry with the doctor, 7 months later:

[I still feel guilty] Because I still should have took her to the hospital. I still should have phoned.. the doctor's office. At least I feel I should have. Because she had such a rough pregnancy, I-, that's the least I could have did. But.. what do you do, eh, like I mean I just totally trusted the doctor... But when we saw him, we know he was very sorry, it's just.. the way he acted. He was very sorry, but.. he said he even talked to one of his colleagues, and there was nothing that suggested there was anything wrong with the baby. Bull crap!

While on bed rest with her second set of twins, Penny also experienced a host of examples of incompetence and poor medical practice. The nurses involved in her care apparently suspected a problem with one of the twins for several weeks when they routinely tried to detect the heartbeat. The doctors, who appeared shocked when the baby was stillborn, repeatedly ignored the nurses' concerns. Penny's specialist and the medical residents involved in her care appeared to make numerous questionable treatment decisions which were detected later by nurses or other doctors. In many of these instances, Penny was made acutely aware of the suspected incompetence because of a lack of discretion on the part of staff:

...about every.. 5, 6 days I would go into labour... they pumped Valium in me, intravenous Valium [to stop the premature labour]. And.. with Valium, you're blood pressure can go way down... So I couldn't--, like you know how you're laying there, and they think you're out of it, but.. I couldn't speak, but I could hear. And.. the doctor gave instructions to the nurses.. and after he walked out, they said, "Well, we'll do what he says, but if something happens to her, we don't want to be responsible." And I laid there, and I'm going, "Oh my God, they're going to kill me."

Twenty-five years after Penny's experience, the death of Christine and Bill's daughter during delivery involved a level of suspected incompetence that led their family doctor to have them lodge a formal complaint against the physician involved. Both Bill and Christine attributed the medical treatment errors as being the most painful and infuriating aspect of their loss:

And the thing that hurts me the *most* about losing Abigail {emotion} was that it shouldn't have happened... once I came out of the hospital, I went to my family doctor, and the first thing she said was, she was so ah.. shocked, she had read the report, and she wanted me to write to the College of Physicians and Surgeons, because, she said that what happened wasn't proper, that I should *not* have lost that girl. What she felt that they should have done was, when my labour didn't progress, they should have decided to c-section, to take her out. And there were several reasons for that... my family doctor says that.. that kind of care, what I got is, is criminal actually. It's malpractice, and... she would like to see that doctor removed. And so would I! Because what if she does it to someone else? (Christine)

It.. it's...it makes me the angriest... months later Christine began to leak urine from her bladder... and it was found [her bladder had been punctured during the surgery after the c-section]. And she was immediately catheterized and told she'd have to wait at least three weeks for reconstructive surgery... a little later [my niece] discovered that we could actually buy an overnight catheter bag. The doctors were not even prepared to properly catheterize her... it.. made for a lot of discomfort, for both of us. There were.. there were many nights {emotion} that she cried herself to sleep in my arms. And it breaks my heart....that we had to live in such pain, even though we did nothing wrong to deserve it... The anger started about the time that Christine's bladder problem was diagnosed. And from about that time on, I think if the doctor had been crossing the street in front of me, I would have run her over. I was that mad. (Bill)

When physicians responded to parents' questions about treatment decisions or errors, they did so in a way that fuelled parents' anger rather than dispelling it. Parents might have respected and forgiven physicians if they had been apologetic and honest about their roles in the deaths, and the parents' grief may have consequently been less complicated. When physicians made any response, however, it was to convey their sympathies but accept little responsibility for the decisions made that might have contributed to the deaths. Luke and Katrina, for example, conveyed how their doctor spoke of taking full responsibility, but then proceeded to place blame on other medical staff, or find other reasons for missing the warning signs:

Luke: ...the reasons he came up, like he was really nice 6 weeks later, after we saw him. But to get him to admit... that he did anything wrong, or dropped the ball.. But see, a lot of the problem I think is, when we had the second bad ultrasound, he went on holidays. And he said he never knew about it... So, it would have been so much easier for us if.. we would have known they'd done everything

Katrina: And then he said.. you know, “You’re reading your paperwork, but you’re there but you’re not really.” I said, “Well, where, where *are* you?” {soft laugh} “You’re supposed to be there.. reading your paperwork.”

Luke: See, we feel worse than we should, ‘cause we feel she that she could have been here... we feel that she would have been here.. if it wasn’t for his negligence... But I don’t know, I guess the biggest problem with us is we’re still so bloody mad about it. That’s one thing for sure, like I’m sure we could talk about him 5 years from now, and you can just tell when me and Katrina talk about the doctor we’re both screaming {Katrina laughs}. We do, our voices go up, and we’re both cursing.

Similarly, Bill’s anger at the obstetrician was amplified because of her response when she spoke to him the night of his daughter’s death:

Dr. Ob finally came in to talk to me. She didn’t know how this could happen in North America. She didn’t seem to see that she was responsible for what happened in any way... she spoke as if she was just a casual observer on the street, just.. not in charge... And what really upset me was the fact that she thought it had happened *to her*. The way she was talking. I found that to be.... totally insensitive and selfish on her part. She told me that she had become an obstetrician because she felt childbirth was a woman’s issue, and was always a happy event.. And I.... I was stunned. {sounding angry} It is not a *woman’s* issue, it’s a *family* issue. And it’s a happy event under the best circumstances. But this wasn’t one of those. How could it happen to her, I could remember her saying that, and..... She said she was sorry for our loss, and she.. apologized so many times. And she cried but.. I gave her a hug, it was like hugging a.. a stone.. statue..... She was very rigid, and she rejected human comfort, which I found completely *odd* and strange.

In addition to negligence and incompetence in medical treatment decisions, other concerns parents with recent losses had were related to incompetence in terms of hospitals’ preparedness for responding to perinatal deaths. For example, in the time immediately after they discovered their daughter had died in utero, Sonya and Owen were appalled that the medical personnel involved appeared uncertain as to how to proceed:

...they’re just kind of sitting there like.. and these are the professionals, they’re just kind of, “Well I don’t know, you might do this, or you might do that, or.. well, we’re not really sure.” And Sonya and I looked at each other, and it was such a *surreal* experience, as if we’re both standing back, looking into this room, going, “What is *wrong* with this picture here?” We’re just struck with this.. *horrible* thing. And we’re the ones that have to manage everything through the process here. Like this, this system was not set up to.. accommodate anything like this. So it was kind of like a third whammy. It’s bad enough, okay, we’ve [just found out our baby is dead] ...and now *we* have to manage the *professionals* through this.

Some of the parents who encountered these various examples of questionable or incompetent medical practice appeared to have lost faith in their hospital or medical system more generally. For example, Sharon articulated her belief that the medical system is based on economics rather than compassionate care, given her suspicion that the hospital was engaging

in passive euthanasia of her daughter. Bill and Christine similarly felt that the responsibility for their daughter's death went beyond the specific obstetrician involved:

I, I think that...not only was *she* negligent, but her supervisor was negligent, the hospital.. ah.. and the hospital board was negligent in how they administered the O.R., and, and the.. use of the O.R. in emergency obstetrics. (Bill)

And then ah, we were asking around, is there *any* good obstetricians in town, who is the best obstetrician, who can I get? And I found out only *after* that you can *refuse* the one that you get... if you want to, if I would have *known*, but see, how did I know that she wasn't good? (Christine)

In trying to explain their doctor's negligence, Katrina and Luke commented that doctors in general are overworked in the Canadian healthcare system. Yet, they did not see this as an excuse for the suspected negligence of their doctor. They also alluded to the understaffed and overburdened system in terms of the long wait for autopsy results. Waiting for such a long time denied them the emotional relief that might have come sooner with definitive answers, as Luke expressed:

...my wife keeps phoning for the autopsy, it may be up to a year.. we could wait up to another 6 months they said... we feel she.. should have been here... that's why the autopsy report's so important to us. Not that it's going to change anything, but if there was something seriously wrong with her... you know, that she wouldn't have lived anyhow, it would make it a little easier I guess...

Three couples with losses occurring in recent years filed formal complaints with the College of Physicians and Surgeons, two at the prompting of their family physicians. Christine and Bill were awaiting the final report from their complaint, but had some satisfaction in knowing that the physician was suspended and her contract was not renewed. The degree to which this eased their grief was negligible, however. Katrina and Luke were uncertain that their complaint would have any lasting impact on the physician:

But we really feel they're on the doctors side too, just by the way we talked to the lady [at the College]. She said, "Well doctors are human too, they make mistakes." (Luke)

...they sent the letter [of complaint] to him. And I wrote in there I want him disciplined for what he did. Even if he's suspended for a month, then he can sit at home and think of what he did. (Katrina)

Dan and Stacie, along with their family physician, wondered if their daughter would have lived if the treatment decisions concerning their daughter's lungs had been different. The response to their complaint held that a legal case was impossible, given that 26 weeks gestation was too early to guarantee survival under any conditions. They accepted the outcome of their complaint

as being reasonable, but continued to find it hard to believe that their daughter would not have lived if the treatment decision had been different.

The couples with the most recent losses (less than a year before the interviews) considered legal avenues for dealing with issues of incompetence, but discovered they had few options. For Katrina and Luke, the cost of IVF was an additional burden in their grief that could not be resolved through legal means:

Katrina: ...that makes me mad, you can't sue in Saskatchewan for stillbirths, they don't consider it. That makes me really mad.

Luke: yeah, like this guy said we couldn't even sue for the IVF... Like the expenses of going again. Like no amount of money would have ever brought her back, but~ ...[The doctor has] basically probably cost us... well, we're hoping the frozen [embryos] will work, but if they don't, he's basically probably cost us 25 grand... And that's a lot of money for us...

Christine and Bill wished they could have launched a lawsuit or charged the doctor with murder, but found these legal means were unavailable to them:

[The lawyer said that] in Saskatchewan, and one other province, I think it's Newfoundland, they're the only two provinces in Canada that don't have the right to sue for pain and suffering. He said the only way I could have sued is if the baby would have lived and required care the rest of her life... But you can't sue for pain and suffering in Saskatchewan. He said the only thing that he recommended that I do is write to the.. Justice Minister of the province and try and get it changed. (Christine)

We weren't given a chance, {emotion} and Abi wasn't given a chance.. ....Had she taken even a breath.. we.. just that one moment, I think we would have charged [the doctor] with murder. As it is under Canadian law, I don't think she can be charged, and even under Saskatchewan law, she is held unaccountable....And she is not liable in any way, she can't be taken to court or sued for malpractice.. (Bill)

In some cases, their experiences within the medical system left parents with traumatic memories that resulted in their grief being severely stifled and largely ignored for decades. Sharon, for instance, blocked out the memory of her daughter being left alone to die, and it was many years before she reprocessed and experienced her grief and trauma in its full intensity. Judi continues, nearly 30 years later, to feel the emotional and psychological repercussions of her doctor's grave diagnostic error. The cruel and insensitive treatment that Irene received, and the memory of her son being born in a bedpan with no medical staff present, were aspects of her buried grief that she had not reprocessed until the time of our interview. And Penny's traumatic experience of medical incompetence and insensitivity over the course of her 3-month hospital stay combined with her grief to have a lasting impact which affected her basic



functioning for many years. Her grief was essentially buried until she sought counselling after her divorce, some 20 years later:

So.. so then ah.. you go home, and I think it took me.. five years.. to finally... I think feel like I was myself again... As my oldest [child] got older, I told her a little bit about it. And then.. it was very hard to tell my youngest one. And, so it's something I never talked about. But when my oldest, one, Paula especially, when she got a little older she would start asking me questions. And I found it really, really hard to talk about.

For those with more recent losses who were traumatized because of suspected medical incompetence, it remains to be seen what the long-term impact will be.

*9.3.1.1.3 A Lack of Compassion and "Cold Professionalism"*

*We cannot keep them from suffering;  
But we can keep them from suffering  
For the wrong reasons*

*~ Anonymous (quoted in Nichols, 1986, p. 157)*

There were clear differences in the levels of compassion exhibited by medical professionals over the decades represented by these parents' stories, with more understanding and compassion for these types of losses displayed in recent years. That being said, a lack of awareness of the significance of the losses and a poor "bedside manner" continued to be experienced by parents whose losses occurred in the past 10 years. As with the other aspects of negative encounters with the medical system, these experiences of "cold professionalism" (Irene's phrase) and insensitivity appeared to have a lasting influence on parents' grief and meaning-making.

All of the women with losses before 1980 were expected to remain on the maternity ward following the deaths of their babies, with no recognition of the anguish of being forced to watch other mothers with their live, healthy babies. Irene recognized that part of the reason for this type of insensitive treatment was the emotional distancing medical professionals practiced in their patient interactions at the time of her son's death:

...well part of it of course was the mores of the time... I know that as social workers, a lot of those people.. they had to have this cold professionalism. Because if you were emotionally involved in any way whatsoever, then you weren't professional.

Refraining from emotional involvement translated into an almost complete absence of empathy or understanding of these women's losses. Upon hearing of her baby's death, Irene's tears were met not only with emotional distance, but also with cruel and uncaring comments from the doctor involved in her case:

And.. this doctor came back... the female doctor. I think she was a registrar, you know, an ob-gyn registrar... it was several hours later, it might have been in the middle of the night. And ah, she said, "Your baby didn't live. Your baby died.".. And I started to cry



again, and she said, *again*, “*Stop* that. You *didn’t.. want.. this.. baby.*” {said slowly, angrily, sharp words} “I don’t need *any fuss* on my ward, on my round.” Um, ver-ry ah.. you know.. “As far as you’re concerned it’s a blessing,” kind of thing, but that’s not what she said, but that was her attitude.

Although Irene did not comment specifically on her unmarried status, it is possible that she would have been treated more humanely if she had been a married woman. She spoke of having the sense of being viewed as less than human:

...very soon after that, within the next hour.. ah, I was very ill. Um, I remember being rushed to the O.R., I remember them giving me blood, and they sent for my mother. What had happened, the placenta had broken up.. probably from the assault .. at the time... And I was haemorrhaging. And I was in dire straits. I knew I was sick when they sent [for my mother] because before then, I mean, I wasn’t even a *person* really, I wasn’t really.. I was a nuisance.

The lack of respectful treatment extended to her baby, leaving her with a traumatic memory that she did not acknowledge until her interview with me:

Ah {crying}..... I wish he.. I wished he was born in the bed and not in the bedpan. I, I heard that sound, it was a horrid sound, I can hear it now. {crying} ...I think I’ve heard that sound before. But I never acknowledged it. {crying, voice breaks} ‘Cause it’s horrible, you know... It’s like no other sound... And it shouldn’t have *happened..* that way. Because after all, I was in a hospital. I was in labour. I was pregnant. You know. Whether it was going to be a stillborn or a live birth, somebody there should have known that.. that.. that ah.. he was *there*. {crying throughout} He shouldn’t have to have been born that way.

Having become a nurse herself many years later, Irene was critical of the emotional treatment she received “under the guise of professionalism”:

...[the loss is] pushed aside, not just by you, but by everybody around you, so it’s~... I have absolutely no knowledge of what happened, what they did [with the baby’s body], what they do do, you know. *Nothing*. [The way I was treated was done] under the guise of.. professionalism..... And I *know* there’s a fine line, I *am* a professional person, I *know* that you *cannot* take everything on board, and *certainly* take it home. But there’s a.. there *is* a big difference between sympathy and empathy, you know, there just *is*.

Deena, too, experienced this cold professionalism from her doctor after her son’s death. His response of, “Oh well, you’re young yet, you can have more,” provided her with the first introduction to having her loss minimized by others. Penny experienced a lack of compassion in the form of complete silence from medical personnel after her 3 losses:

And then ah.. the ah.. yeah, there was no concern, there was no follow-up, there was no one coming to ask me how I was doing... especially, they said, well okay... have a good life and whatever, and blah, blah, and that was it. No one asked how you were--, there was nothing. Absolutely nothing, like I was never given a record of anything.. absolutely nothing. It was like it had never happened.

Judi and Sharon both commented that they experienced kindness and compassion from some of the medical staff, but glaring absences of compassion from others. As Sharon expressed, “There were times of great compassion through the whole experience, and times of.. not. Real inconsistency of compassion in dealing with a very tough life experience.” Judi spoke of standing beside her son’s incubator for the 9 hours that he lived, with no offer of a stool to sit on, and no consideration that allowing her to hold her dying baby would be a more compassionate way to treat both mother and baby. In Sharon’s case, the greatest display of uncompassionate care was toward her baby, with Sharon’s suspicion that passive euthanasia was being used with her daughter.

Despite the great strides in the past 20 years in medical professionals’ understanding and treatment of parents dealing with perinatal loss, problems still exist with inconsistency in compassionate care. As Stacie put it, “They just picked the wrong times to be sensitive and insensitive.” Dan related a number of instances that he experienced as insensitive handling of the situation by medical staff, including the doctor who informed him over the phone of his daughter’s death, as well as being asked at such a traumatic time whether he wanted his twin babies involved in a research project testing a life-saving medication for premature babies. In Sonya and Owen’s experience, the obstetrician who informed them that their daughter had died in utero displayed a lack of sensitivity in delivering the news:

[The obstetrician on-call] came in, and just sort of said, “Oh, your daughter’s dead.” He went, just, “Your baby’s dead.” And of course.. me thinking I’m hearing my daughter’s heartbeat, just *2 seconds ago*, saying, “What are you talking about!?” And, “Look, this,” *literally*, he said – it’s so vivid in my mind – you know, he points to the screen and he said, “There’s no heartbeat. This is where the heartbeat should be. There’s no heartbeat. Your baby’s dead.” {said in a cold, business-like voice} And *that’s* the kind of compassion I got out of that asshole. Um.. you can bleep some words out. {soft laughter}

Finally, Luke and Katrina were confused and angered by the discrepancy between their obstetrician’s friendly demeanour during their prenatal visits and his behaviour during the delivery of their stillborn daughter:

Like he comes in, when he [came for the delivery], he says, “Well I left a person laying on the operating table.” Well what was I supposed to think, he was a hero or something? (Katrina)

...he was terrible, in the delivery room with us... He was, he was such a nice man ’till then. He was just cold.. and heartless.. he.. just totally changed. (Luke)

#### 9.3.1.1.4 “Times of Great Compassion”

While the preceding discussion focussed on the most negative aspects of parents’ experiences of the medical system, it is important to emphasize that not all experiences were

negative, and not all medical professionals, recently or decades ago, were insensitive. Rachel's experience, occurring in the late 1970s, contained no instances of insensitivity, aside from possibly being avoided by staff afterwards to some degree. She recalled being treated compassionately by the nurses, particularly the head nurse who delivered her baby (she was trained as a midwife in Britain):

So that midwife was wonderful, she helped my husband the next morning with all the forms he had to fill in and.. the funeral arrangements and things like that, she was.. really good... So I spent one day in the hospital.. And like I.. I felt I was treated.. well, I guess they avoid you as much as possible. But.. I mean, nothing bad happened. And I.. don't think I would have.. cared whether anybody really said too much or not anyway... the shock I think just kind of numbs you at first... But.. the hospital experience wasn't.. wasn't terrible.

Rachel speculated that the difference between her experience and that of most other mothers during that time was that her baby was born in a small hospital and she was therefore less likely to "get lost in the shuffle." Another possible factor in her unique experience was the meaning she attributed to her son's death. That is, because of her outlook on life, she may have dismissed some instances of insensitivity (although she clearly did not experience some of the blatant insensitivity or incompetence that others did):

I thought I was treated well. Like not knowing why he died, I'm sure that nowadays they would have been able to figure that out... But.. to me it doesn't really matter. I mean... I had him, and he.. for some reason.. died, and that's the way it is. And some people just need those answers, if they're still thinking about that now, still going over it. Like I haven't been like that, I~ it's accepting I guess ...if there's a blame to be--, like I've heard of babies that, when something's been done wrong during delivery and the child dies, like I... seems to me I would have a very hard time accepting that.

Individual medical professionals who parents experienced as being compassionate appeared to exude qualities such as kindness, humility, empathy, and sincerity. During her hospital stay, Sharon encountered a number of kind and compassionate nurses and doctors whom she described in terms such as these. Some parents told of gestures made by hospital staff that communicated respect for the personhood of the baby, and acknowledgment of parents' rights to decide who could see the baby and how much time they spent with the baby. The NICU nurses gave Dan and Stacie matching mementos for their twins during their son's stay in the hospital, so that they would have tangible memories of their daughter. Mona recalled the care with which her nurse collected memories of their baby girl and bathed and dressed her. Mona's experience also demonstrates the value of medical professionals expressing their sympathies and quietly accompanying the parents in their early grief:

Dr. Neonatologist was the.. neonatal doctor who was in there. And, he came over and.. you know, was very, very sympathetic to us, and.. said that.. you know, we could hold

her now...and Dr. OB2, you know.. most of the time they're so.. in and out, the doctors, it's the nurses who deal with--, but she sat for a long time with us. Which was wonderful... and our nurse stayed with us all day. She was in and out all day.

Sonya spoke of her great appreciation for the hospital policies and specific training of staff to deal with perinatal losses that was apparent in her experience. The easing of grief that such hospital policies and individual staff members provided was not just at the time of the interactions with parents, but also in terms of long-term grief and the parents' ability to make sense of their experiences over time:

And so finally they did take us up to labour and delivery. And that's when everything changed. Ah.. labour and delivery at our hospital.. knows what they're doing, and they do it well. I'll give them major kudos, except for the minor.. one or two nurses that came in.. in between. But they must have nurses that are trained, on staff, which I think is.. incredible and should be put in place everywhere. Because these were.. very compassionate, well-trained nurses to be able to handle our situation. So.. they brought us into.. the biggest room they have, which I thought was very nice. And then, once we were there, then everything changed, because the nurses took over, and they were much more compassionate than the people we were dealing with to that point.

The importance of hospital staff being compassionate and sensitive to parents' grief was particularly evident in Sonya's story of having to turn her daughter's body over to be taken away after saying goodbye. The trust she felt for her nurse made this extremely painful task somewhat easier to bear:

Ah, and our nurse, who... just was so wonderful when we were~.. Like we had 3 nurses, and they were just.. very compassionate and very wonderful, and it just, it really made a big difference. And she was having to go off, and.. I just.. {sigh} I guess I had to pick a time, or we had to pick a time when we had to say goodbye. I didn't want anybody else to take her down... to the morgue, other than [that nurse], 'cause I knew she would be really careful with her and cautious with her and stuff like that. And so actually otherwise I don't think I would have let her go. {crying} That was hard.

#### *9.3.1.2 Influence of Social Ideologies and the Response of Social Networks*

*I had all the support that a guy could ask for I guess, but still, it was my wife and my child in the hospital. And no matter what anybody could do for me, it seemed like my whole life was upside-down...(Dan)*

*And like I said, I just... I couldn't get over how.. {crying} ..beautiful the support was, but...{sigh} but it doesn't change it. (Christine)*

*It's just terrible the way that people.. because they haven't met the baby or something, they're just terrible about it. (Luke) That hurts me more, almost, than losing the baby. (Katrina)*

The voices of social networks were loud and clear in each of the parents' stories, some with compassionate and supportive messages, and others with insensitive and emotionally

scarring messages. Like the medical establishment, parents' social networks – family, friends, co-workers, acquaintances and other people encountered within society (e.g., clergy, funeral home workers) – were involved automatically and influentially at the time of death. Additionally, the ongoing influence of many members of the social networks extended throughout the years, along with the influence of new contacts encountered over time (e.g., new friends, counsellors). The “involvement” of social networks often meant the *absence* of comments or contact, rather than active involvement. As the above quotes illustrate, while parents greatly appreciated positive responses from their social networks, they emphasized that nothing could take away their grief; on the other hand, negative responses from their social networks played a potentially powerful role in accentuating the trauma and grief over the losses. In essence, the power of a positive response from social networks cannot be fully appreciated without considering the damaging effects of a negative response. The messages given to parents through these responses, whether positive or negative, invariably became a part of parents' meaning-making and affected the course of their grief.

#### *9.3.1.2.1 Social Ideologies in General and Social Understandings of Grief*

The social climate and ideologies of the period that each parent lived in determined, to some degree, the response they received from their social networks. Bereaved parents and members of their social networks were tacitly influenced by the prevailing views and ideologies of the time in their attempts to account for and respond to the babies' deaths. Collective views on loss and grief clearly came into play, as well as views about general issues such as gender roles, responsibilities of pregnant women, and childbirth.

General Social Ideologies: As an example of social ideologies that influenced parents, the historical tradition of men not being a part of childbirth meant that some women were alone at the time of their losses. Deena and Penny were both alone when their babies were born and died, and neither of their husbands provided any support or displayed their own grief afterwards. It is possible that responses such as these were specific to the individual men. Additionally, however, societal views on childbirth, men's roles in pregnancy and childbirth, the acceptable level of involvement of men in caring for infants, and men's grief likely played a significant role in determining how these men responded to their babies' deaths and their wives' grief.

A second example is the gradually changing view our society has of single mothers. Irene and Judi were both affected by the stigma attached to being an unmarried mother that existed at the time of their babies' deaths. With a surviving child at home when her son died, Irene faced the financial reality of being a single mother in a society that scorned and provided little support for women who became pregnant out of wedlock. It is understandable that she

would bury her grief under such circumstances, as is the psychological impact of the meaning crisis of her unprocessed losses and traumatic experiences (i.e., loss of self-esteem, repeatedly entering into abusive relationships, alcohol abuse, mental illness). In Judi's case, her painful awareness of the stigma attached to her single mother status added to her sense of being abandoned and alone in her grief.

In other instances, mothers were affected by contradictory views on women – such as the great responsibility placed on women for keeping their pregnancies intact (leading to agonizing guilt when problems occurred) coinciding with the historical view of women as emotionally and mentally fragile (evident in attempts to “protect” bereaved mothers by not mentioning the baby). The silence many of the mothers found themselves in after their babies' deaths left the mothers wondering if others blamed them as they blamed themselves; alternatively, they questioned their strength and sanity since they felt such intense grief while no one else seemed to view the death as significant.

Time Limits on Grief: With respect to society's views on grief, some parents told of encounters with others after their babies' or other family members' deaths that portrayed the view in western society that grief in general should be short-lived, and the bereaved should resume the appearance of normal functioning within weeks, if not days<sup>23</sup>. In some cases, the parents themselves felt they had no choice but to enforce such expectations on themselves. Deena, for instance, felt she was unable to fully grieve for her brother when he died, attributing her stifled grief to having to take over his job immediately after his sudden death. Stoicism, quickly returning to one's normal activities, and composure were qualities that social networks appeared to value in the bereaved parents. For example, Bill described his boss admiring how composed Bill was at Abigail's funeral: “My ah.. boss at work said to me that I handled it so well at the funeral. And I laughed to myself afterwards, thinking, I wasn't handling it, I was putting it on hold...”

Misperceptions about how long intense grief should last were common. Sonya spoke of trying to assure her father that his grief over his wife's death would not be resolved quickly, as her sister expected:

I was trying to use my grief with Alanna to help [my dad] with his grief with my mom. Because everybody's trying to rush him through it... I mean 4 weeks after my mom died

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<sup>23</sup> This may relate to the never-ending quest in western civilization for economic and time efficiency in most aspects of our daily lives – faster computers, more efficient vehicles, faster recovery from physical pain and illness, and so on. While some such quests lead to positive societal changes, speed of “recovery” and economic efficiency in the personal and emotional realms of life are not necessarily beneficial to individuals or society.



he was supposed to be better, according to my sister. And it's like, "No Dad.. all I can say is that.. it's going to hurt and it's going to take a long time, and.. just hang in there, and you'll be okay, it will start to ease up, but it won't be for awhile, and just know that this is normal."

Sharon recalled trying to explain to a friend her angry response to society's time limit on grief:

I said, "You know, I had my mother tell me to stop crying after 3 days, and my husband telling me at 3 or 4 weeks that it's time to move on, that's enough grieving, it's time to get on with life." And my friend, who's never experienced a loss of anybody very close to her, she just couldn't *get it*. And that to me exemplified how general society feels about loss. It's like, "Come on! It happened, get over it already! What's going on?!"

Four months after her daughter's death, Christine spoke of already noticing the expectation being imposed on her to "get over it," despite the initial outpouring of sympathy:

...it's so nice to have the support of the family. And, especially the first month after. You know, there's so many people around... But now that.. you know, now that Christmas is over, and the whole thing is over, now.. it's the idea that life should get back to normal? ...I notice it [happening] a lot... And sometimes when you start to.. to bring it up a little bit, you know, you can tell right away that it's not appropriate.

While some of these examples might demonstrate the disenfranchised nature of perinatal loss specifically, it was evident from some parents' experiences that similar reactions from social networks occurred after other losses as well<sup>24</sup>.

Men's Grief: Another area in which societal views on grief came into play was the grief of fathers. Deena's and Penny's husbands' cold and harsh responses, for example, were perhaps a reflection of the view at the time (1960s and 70s) that men should control their emotions in matters of grief, remaining strong and refraining from being affected by loss. This was likely particularly true in terms of a baby's death, for which the message given to parents was to forget and simply have another child. Penny recalled how her husband's response resulted in stifling her own grief:

But all those years I [didn't let myself cry over anything] because.. you know, I.. just something you thought wasn't right. And then my ex didn't understand. I know he probably grieved in his own way, but, "Life goes on, so what." And so.. that.. was hard. I never had someone.. considerate.. to help me deal with it at all. So rather than having him bark at you when you're crying, then you.. choose not to cry.

The experiences of the 5 men who participated in this study, with losses occurring since 1995, suggested that this stereotypic western male model of how to grieve is still prevalent. Unlike Penny's and Deena's husbands, however, these 5 men were unguarded about admitting to grieving very deeply for their babies, despite the implicit societal message that they should be



strong and unemotional about loss in general. As well, these fathers revealed that their losses were as significant and life changing for them as for the babies' mothers. These men's stories also showed that guilt was a part of their grief too, rather than being specific to women experiencing a perinatal loss. These findings are contrary to the expectations of society (which the fathers adhered to themselves in some cases) and preliminary evidence in the research and clinical literature that suggests men do not grieve as deeply over miscarriages and perinatal losses as do women (e.g., Beutel, Willner, Deckard, Von-Rad, & Weiner, 1996; Leon, 1990).

Some of the men showed evidence of conforming to stereotypical responses initially, but later changed their behaviour and their views on how a man should grieve. Andrew, for instance, spoke of initially adopting the stereotypic male model of grief which he had witnessed in the men around him. He attempted to be a strong, supportive, stoic man who did not cry. In practice, he encountered the reality of trying to hide his grief: "I took it like a man, and the way I took it like a man was I poured a bottle of booze down my throat." Ultimately, his aboriginal cultural roots helped him to set aside the male grief ideology he had implicitly accepted, and allowed for the release of emotions in a way that is rarely seen in the broader Canadian culture. Dan, too, spoke of trying to follow the gender norm of appearing tough throughout his life, in response to being bullied as a boy. When his daughter died, he was joined by the men in his family in openly expressing his grief, and he no longer cared whether or not he was viewed by others as being a tough man. Mona also spoke of her husband conforming to the stoic model of how a man should grieve, which he abandoned to some degree when their daughter died:

I saw a side of him that.. wasn't.. there before... you know, I found out.. that when his grandfather died, that he was very close to, he never cried at the funeral because his grandpa had told him.. like he had seen him a few hours before he died, and he said, "You know, real men don't cry. So don't you shed a tear.. when I die." And.. he said he didn't. He didn't cry once at his grandpa's funeral. And, he said anytime.. *anybody* that they know has died, he's always the one in that--, in their family, to be the *strong* one, and to be supportive of everybody. And he said, "That's what I'm used to doing, so.." But, he was able to finally.. at least with *me*, he was able to show his real emotions, you know... he was able to show it with me.

Other fathers suggested that the losses were harder for their wives to bear because of the physical aspects involved<sup>25</sup>:

...but you know what though.. I was very upset and sad by what happened, but it's got to be a lot different when you're carrying the baby inside you. It's got to be a lot tougher.  
(Luke)

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<sup>24</sup> This is also consistent with what has been reported in the grief literature (e.g., Walter, 2000).

<sup>25</sup> Note that both of these fathers are referring to their babies being stillborn.

And it was very hard on Sonya, I mean.. I mean it was bad enough for me, but it was.. 10 or 100 times worse for her, really. Having to go through the business with.. expressing the milk and all that.. and the pain and all that and the frustration that goes with it... And like I said, then the business with blaming yourself and that sort of thing. So it was orders of magnitude more difficult for Sonya than it was for me. (Owen)

Yet, the comments these fathers made, and the emotion they showed, suggested that they grieved very deeply for their babies.

What was supposed to be the happiest--, I can't ever remember going through anything so bad. Like I've had people I love die, but.. Everything we did for a year was based around that little girl coming. (Luke)

But the thing of it.. and I'm really sincere about this for Sonya, is that.. because she took such good care of herself.. and she really truly did, and she was remarkable.. {crying} that.. because of that, that ah.. Alanna actually made it to the end [of the pregnancy] {whispered, crying} So at least.. at least I got to hold her for awhile. {sobbing} (Owen)

Perhaps their comments about the losses being greater for their wives reflect, in part, the gendered cultural norms to which they felt pressured to conform. Their comments also reflect the responsibility they felt to take care of their wives before themselves, and the helplessness they felt in knowing there was nothing they could do to take away their wives' pain. Bill's experience is a clear illustration of the emotional neglect and the challenges fathers faced during their early grief:

And I {emotion}.. I knew I had to be strong that day, for Christine, and for my mother, and for Dawn. And then I.. cried when there was.. nobody really looking. The focus was on Christine, she was still in a wheelchair. Um..... in looking back I would say that ah..... {sigh} as a grieving parent, the father is.. very much overlooked. And ah..... at the time, I understood, because I could see what was happening to Christine. And my focus was on her too. And in a way she.... without realizing it, was denying me that right to grieve.... It wasn't that she made the decision to say that, or to do it, but the focus was.. I found myself focusing so much on her.. that {emotion} I had a very difficult time..... There was times I'd hear a song on the radio, and I'd just be bawling. {emotion} And.. anything involving a child.. or anything involving loss. Often I drive in to work in the morning, and I'm alone and I have the radio on..... and often there are {emotion} a lot of tears that came out because that's the only time I was alone, and I could grieve. Christine needed my care and attention, and so did Dawn. And grieving around others just.. um..... it didn't seem like an option at the time.

Also mentioned by some of the men was how they viewed the expectation and necessity for fathers to return to work very shortly after their babies' deaths. Luke and Bill commented on wanting to return to work in some respects because it distracted them from thoughts of their losses. Luke, for example, had a hard time being at home with the thought of his daughter being dead:

I had 3 weeks holidays planned, plus I got a week because of the little--, our little girl dying. But I was even thinking of.. cancelling my last week, because I just couldn't sit around anymore. It was just too hard knowing that we didn't have our baby... I was exactly the opposite of Katrina. It was driving me nuts, sitting at home thinking of our baby not being here. But everyone's different... It drove me.. insane.

Although Bill felt neglected as a grieving father, he recognized that returning to work helped him to return to "the world of the living:"

[Going back to work as soon as I did] was necessary, but I think, ah.. the funeral was on a Wednesday, and I'd been off work at least 7 days, or 8 days. It was necessary, we needed the money. But... in psychological terms, maybe, too, it was necessary to be doing something positive... it was necessary for me to.. return to the living.

In contrast, Dan's comments revealed the other side of the return to work issue for fathers, who typically receive far less bereavement leave than do mothers:

I tell you, Daddy hurt a lot... and everything was out of control, and you're standing there, and you're helpless... The way I look at it, I get my 3 days.. you know, of grievance time. Suck it up, walk back into work. My wife's in the hospital, my son's in the hospital, my daughter's dead... And to walk back into work, and I've *known* these people forever... That was probably, next to everything that went on with her, that was the *hardest* day I had, after all of it was done, was to go back to work. You know, and ah.. suck it up.

Lack of Societal Norms for Responding to Grief: Some parents acknowledged the uncertainty social networks likely had in knowing how to support the parents in their grief, and they referred to their own pre-loss difficulty responding to others' grief. Western society generally lacks norms for how to respond to death and grief. This leaves members of a bereaved person's social network at a loss as to how to respond sensitively and appropriately, particularly if they have not had a previous experience with loss themselves<sup>26</sup>. As a result, many people say as little as possible or nothing at all, or they express their sympathy indirectly by speaking to the bereaved but avoiding any mention of the deceased or the ensuing grief. Katrina and Luke, for example, recognized the predicament many in their social network were in, based on their own difficulty knowing how to respond appropriately to others' grief before their daughter died:

Luke: [Some friends] realised how bad it was for us, but not.. people in our own family. {soft laugh} I don't know. But you know, I don't know how I'd.. if I knew someone that had a stillborn, or a baby that died just after being born, would I be the same as them? Maybe not now, but would I be if this was~.. I, I admit, it.. when I think of it, it would be hard... It would be tough to say.. what do you say?

Katrina: Sorry. Now I could know what to say...At least I know I can phone other people now if something happens... even after my dad died, I could find it hard, like if people

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<sup>26</sup> Dyregrov (2003-2004) refers to this as the "social ineptitude" of a bereaved person's social network.

died, I didn't know what to say. But now after losing Brittany, I can actually phone somebody and ask how they're doing, and~

Luke: Well you're a lot better at that than me... But that's why I don't get really, really upset when people just ask how it's going. Like it depends who they are, some people have said sorry, some people say nothing, and I don't let it~... But like you said, if it's people that you know a little better, it hurts a little ...but I guess everyone, when it's death, a.. a lot of people have problems, when it's death, anyhow, generally.

Bill took a similarly sympathetic view of the discomfort shown by his social network after his daughter's death:

I realize that [many people] have no experience of what I'm going through. And I.. I can't hold them responsible for their misunderstandings, and, and lack of knowledge in this area. What I...went through at work, the first few days, there were a lot of awkward moments with people until they began to realize that I wasn't made of porcelain and I wasn't going to break.

In response to her experience of losing her daughter and the uncertainty displayed by her social networks in response to her grief, Mona changed her personal response to deaths that occurred within her social network:

But.. I sure.. view.. any kind of death differently now. Whenever I hear about something... you know, I don't ignore it now. When somebody that I knew died, I never sent cards before. And now I make sure I do. And I try to be as supportive as possible in it, without saying anything that I think would offend somebody.

Christine, too, noticed the discomfort of others who were anticipating her new baby. While understanding their discomfort was likely a result of not knowing what to say or how to begin, she was obviously hurt by their response:

But.. now I've noticed that--, okay, I take Dawn to a little play group, and I had gone there when I was pregnant, 'cause Dawn was just little then. And then I told them, you know, I'd be back with two babies, and they were all so nice. Well after I lost the baby, I went back to the play group and I noticed that the mothers were.. shy to talk to me {emotion} They shied away, eh.

Christine's and Mona's stories also highlighted issues unique to perinatal loss for which social networks displayed particular uncertainty and discomfort with knowing how to respond.

...I don't want [other people] to forget that she was real. So I want them to be able to, like, to talk about her a little bit. You know, and, like and I tell them, you know, don't worry, and especially the pregnant ones, you know, they're scared to say anything about their pregnancy, because I lost the baby. But because of Dawn, I can talk about Dawn's pregnancy too, it makes them feel a little easier. (Christine)

...it took about a good 10 months for my closest friend to finally ask me about it. Which.. surprised me. They back[ed] off.. my two best friends, they didn't talk to me for 3, 4 months after Hannah died. 'Cause both of them were pregnant. So they didn't know what to say to me... I didn't get to be a part of their pregnancies and their life, because they

were shutting *me* out, because *they* were uncomfortable. *I* wasn't uncomfortable, because I had no problem talking about it. I *wanted* to talk about it. To me it felt better to talk about it. (Mona)

In recognizing the difficulty their social networks had in knowing how to respond to their losses, some parents took the responsibility of initiating conversations and educating others on what type of response was helpful. Mona, for example, spoke of initiating conversations despite the clear discomfort of family and friends:

...sometimes family gets weird if we start talking about it. I talk about it. Trent never talks about it, but I do. Sometimes they like.. they, they don't want to talk about it. It's like it bothers *them*.. to talk about it. It bothers them to see *me*.. being okay to talk about it, I think, sometimes... Two of my closest friends, now though, they have sat with me, and I've told them absolutely everything, and they've been *very*.. *very* good about listening, and asking questions, finally. But it, it did take.. you know, 6 to 8 months for anybody to finally.. *talk*.

Katrina also chose to educate others by responding honestly when offered platitudes or asked how she was doing:

Katrina: People ask me how I'm doing and I'll say it's been hard.

Luke: And then they just go blank, they don't know what to say... Let's face it, a lot of people don't want to hear about a stillborn.

Katrina: I don't care, I'll tell them... If they ask me how I'm doing, I'll tell them. 'Cause it's good for them to know. And when people say it was meant to be, I say "No, it wasn't meant to be." ...It's good to educate people, they should know about it.

Rejecting Societal Views on Grief: While many parents alluded to accepting socially derived views of grief before their losses, they also displayed signs of changing or changed personal views of grief because of their experiences. As mentioned, Andrew and Dan had both conformed to the stereotype in western society of men displaying stoicism and toughness in the face of adversity, which they abandoned after their daughters' deaths. Irene spoke of being influenced for many years by societal "voices" that led her to be afraid of being sad, and her eventual understanding that sadness must be felt:

I think now I'm.. I might.. I *will*.. *allow* myself to be sad for awhile. {quiet, near whisper} I used to be *afraid* of being sad, you see, 'cause I thought sad was~.. well, *first* of all, you couldn't get on with doing things, you know, get on with it, you know, "*Pull* yourself together!" you know {soft laugh} those voices. And I'm not afraid of being sad, anymore. ... I'm not saying it's *pleasant*. {laugh}

During our interview, Luke voiced some concerns about his and Katrina's response to their daughter's death that suggested he was still influenced by societal views on grief. For example, he expressed concern over Katrina's "obsession" with reading stories of other parents'

experiences of losing a baby. He appeared to be reconsidering his concerns based on our three-way discussion and having a chance to talk to me, a fellow bereaved parent who had experienced a stillbirth as well. He seemed to have longed for someone who had “been there” to tell him what was normal and what was not.

...one night we were at a hotel, and there was a ton of [stories about stillbirth on the internet], it was just unbelievable... but [Katrina] was just obsessed with reading stories about people that had lost babies... and I understood, but I just didn't think it was serving any purpose... Well I didn't mind it for awhile, but like I mean it's just.. when you're doing it hour after hour.. it was just continually... I was just worried about it making things worse... But if it can make things better, I guess, like you said, who are we to judge whether.. it's going to make things better or worse I guess.

Finally, Bill spoke at length about his previous knowledge of early grief theories (stage-based models) which he had read about several years before. He appeared to have accepted the picture of grief portrayed by such theories, but was questioning some of what he had learned based on his experience of losing his daughter four months earlier. Like the other parents, Bill found that society, and grief theorists, did not have all the answers about the grief he was going through.

I can remember seeing funerals as a child, and I remember seeing that.. generally speaking, a grieving family didn't do a lot of crying, even at the funeral.. sometimes, there were occasions. But grief is something that, in our society, is something that, I've noticed people keep to themselves. And I was trying to do the same thing.

I remember.. seeing other people in the grieving process...And I guess there's.. the [thoughts] in the background, and you would think, well why can't you just get over it? But going through it now, it's not something that you choose, it's something that happens, it's something that we go through. You *cannot* control it.. Even though we try to push it aside and try to direct it in certain ways, it is a process, and the books told me that it takes six months, on average... I remember.. reading a few pages of Elizabeth Kubler-Ross's book, “On Death and Dying” many, many years ago, but...

...really what it has been is, getting to live with it. Getting over it? ...I don't know... there's part of me that grieves, and there's part of me that.. that feels like I don't grieve enough, and a little bit of guilt in *that* sometimes. And I think too, there's also that element of, of holding off the grief, not permitting myself to grieve.

#### *9.3.1.2.2 A Disenfranchised Loss*

“Conspiracy of Silence”: This was the term used by early perinatal loss researchers to refer to the silence that engulfed mothers after experiencing a perinatal loss, the absence of any mention of their babies or their feelings about what they experienced. The parents in this study experienced a similar phenomenon, with those whose losses occurred before the 1980s recalling the greatest degree of silence from their social networks. These silences served to



reinforce the disenfranchised nature of the loss, giving mothers the message that what occurred was so insignificant that it did not warrant mentioning, let alone grief.

Irene's story illustrated such silences in the form of surreal conversations in the hospital after her son's death, which avoided any mention of a baby:

All my mother and I talked about... wasn't the baby at all.... It was almost as if I had some sort of surgery.. but it had nothing to do with a baby, or a live baby, or a birth – *nothing* like that. It was as if.. I kind of felt.. that to *please* this doctor and to *please* my mother, I should say *nothing* about this. It was almost as if that had never happened. It's very hard to explain what, *what* was supposed to be happening, except that~ And then after this.. first surgery, I remember my mother being there. I'd said to my mother, "I'm passing lumps." Not just bleeding, but passing lumps. They got the doctor *again*, and I was rushed to the O.R. again for a D&C. Because there was obviously still some things left. And even *then*... the word placenta wasn't used. It was "haemorrhaging" it was "blood," it was.. "female," I remember that. But it was not~

Deena, too, had little opportunity or encouragement to talk about her son or grieve openly for him ("everybody shut up"). Penny described the silence surrounding her losses, which extended to having to tell her children about the baby's death herself on her return home because everyone else refused to talk about it:

I don't think I ever talked to anybody about it... And then ah.. life went on. It was never ever brought up or talked about or anything. And you know.. I guess when you think back, no one even.. you know, ah... if they would have lived you would have got a gift, you would have got something. This, you don't even get a card, sorry to hear, absolutely nothing... And like his parents spent a lot of time, 'cause it was their farm, so they were out there all the time, and.. [my mother-in-law] would never want to talk about it. With my first twins, she.. she just said, "It's over and done with, don't ever talk about it again."

The silences were less deafening but still a common response of the social networks of those parents whose losses occurred most recently. Luke, for instance, attempted to make sense of the silence of some friends and family members, speculating that the discomfort they noticed in many cases was specific to the death of a baby:

It's just terrible the way that people [respond].. because they haven't met the baby or something, they're just terrible about it... The people around you don't want to talk about it, they don't even bring it up, they don't even want to say sorry... People just don't want to talk about it when it's a baby that died... I, I'd like "sorries" from people I know a little better, but that hasn't even happened. But.. some of these people sent flowers, and knew about it, and said they just didn't know what to say, and that's fine. But yeah, even.. like I'd seen a few of my aunts and uncles, and I thought they might have.. once again, they sent flowers, they didn't say sorry, but maybe I shouldn't.. have expected it, I don't know.. {laugh}... I know in our family, generally we talk about things, and I don't think [a baby's death is] something very comfortable.. well, I'm not saying they haven't all been very nice, but it's generally something they won't bring up. And I think that's how anyone.. it sure seems, like from what I've seen, people just aren't comfortable talking about it.



“No Concept”: Platitudes, Comments, and Actions: The decade in which the losses occurred was not a determining factor in whether parents were offered platitudes and other offensive comments from their social networks. While some were likely said with the intention of comforting the parents, these platitudes and remarks clearly had the opposite effect. As the following excerpts demonstrate, most parents were angered and hurt by the insensitivity and minimizing of their losses that was conveyed to them through such comments.

And what I got, when I first came home, was, “Oh well, go ahead and have another baby right away.” “That’s the only way to get over it,” I was told. Well... for me it wasn’t. Sure, you can have another child, but it’s not the same as the one you had! (Deena)

...some of the cards that I got, after Hannah died, they almost made me mad, when people would say things like, “Well it’s God’s way.” Well no! To me, no, that’s not right. Or somebody saying, “We know how you feel.” But yet they have 6 children and they never had any kind of loss. (Mona)

I got really sick of, “Well, it was probably for the best.” ...Why is it probably for the best? And.. oh, “Well, something might have been wrong with the child.” Well~ It’s one of those.. okay, there’s no proof anything was wrong. But even if she had spinal bifida, I would rather have a child with spinal bifida! I would rather have a child with Down Syndrome! I would rath--, you know... you’d have your *child*... “Oh, well God chose to give you the easy route, and he just took that little angel right up with~” *Don’t* tell me that! {laugh} you know. (Stacie)

Don’t say it’s in God’s will or, you know all the~ ...we’ve heard all of them, and it’s maddening, some of the remarks you get. “It was meant to be..” *Don’t* tell me--, don’t use those sayings, “It was meant to be, it was God’s will, he had better plans for him,” whatever. That’s all garbage. (Luke)

In other instances, family or friends gave parents explicit messages that the death of a baby was less significant than other types of losses, or that their losses were not so great that they should continue grieving (or crying) beyond a few days or weeks. The comments were not always explicit, but the overall perception parents came away with was that their social networks did not see their losses as significant. Sharon, for example, perceived that some remarks made by others implied that her daughter was “defective,” and her grief was therefore “different” and not as deep as for a spouse or parent. Penny recalled the thoughtless comments made by members of her social network after each of her losses that revealed the degree to which her losses were not recognized as being the deaths of her children:

I had neighbours, they were just so--, like, “Oh, you must feel very privileged, ’cause you had twins.” Well, they were *dead*. You know, they said some.. cruel things... [After Cora’s twin died] I think ah.. like a lot of people, the comments were made, “Oh well, at least you’re lucky you have one.” That’s the comment that everybody made. “Oh well, you have one. Well, that’s better than none.”

Likewise, Judi recalled a blatant example of a family member denying the significance of her loss and her son's life by refusing to include her son in the family tree. Luke conveyed the feeling he came away with after encounters with some family and friends:

I can remember even talking to [a family member] once, was it even a month after the baby had died? And he said, "Well it's time to get on with things, and.." I don't know how he said it, I thought.. jeez.. never got a sorry from you or anything, and.. now you're saying it's time to just forget it and get on with things... Like really, people do really think you should just get over it overnight. That's what's made me the maddest... I really do get the feeling that people think it's no big deal.

Sonya, too, expressed her disappointment with her family's response, feeling that their comments and actions showed that they had "no concept" of the grief she and Owen felt. It was difficult for them to make sense of this mind-set, but Sonya was determined to voice her needs and her outrage at her daughter's existence being denied by others. Although lengthy, this example is an excellent illustration of how loss-disenfranchising reactions by social networks can influence a couple's grief and meaning-making. It also illustrates how parents whose losses occurred in recent years displayed a more assertive stance in the face of negative reactions by others<sup>27</sup>.

Owen: I'll say something, and it will sound really bad, but I think... it's almost as if it's a real embarrassment [to some family members], that this happened. And let's just.. set it aside, and forget about it. And, and that was really difficult, when Sonya's mom passed away here, and they were doing up the obituary, and it was.. "Predeceased by.." [and Sonya wanted Alanna's name in there] and her sister was, "Well why would you want to do that?" So that was very.. very hurtful for Sonya to watch that. And ah.. I, I.. don't know.. one of these days maybe I'll figure it out, I don't know what it is, I can't.. I don't know why. And particularly her sister would be.. like this.. I don't understand... Like it's, it's one thing just to forget [about including her name], that's.. well, okay. But to have to.. ah.. to have to fight for it, it's very frustrating, very disappointing.

Sonya: Yeah, and then when the priest came to visit us at our house, he was asking, you know, how many grandchildren my mom had and stuff like that, and of course my sister pipes up, 'cause she's got the two, and ah, I got the dirtiest look when I said, "And she had another granddaughter, Alanna, my daughter who died at birth." Like I told a family secret, like some horrible thing.. and it was just.. that, that's.. denying the existence of my daughter. Makes me really upset.

Owen: Yeah. And if I try to understand anything in life, it'll be that, 'cause I don't understand even why?! Like why would somebody else.. I don't know, I mean the only

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<sup>27</sup> The reasons for this increased assertiveness are likely numerous and varied, possibly reflecting ideological changes in western society such as: the shift toward openness and self-revelation in terms of personal problems and emotional issues (Walter, 2000); over time, open mourning and grieving is more accepted and grief is better understood by society in general; for the mothers, the women's liberation movement and increasing gender equality in western society means that the women are "allowed" to be assertive and recognize their strength and potential in a way that did not exist for the older generations.

thing I can think of is, if it's an embarrassing thing or something, I don't know, it's.. Like I can see if you have a serial killer as a relative or something, that'd be one thing, but-

Sonya: She was an innocent little child. But [my sister] has problems with a lot of things in terms of grief and things like that, I think, ah.. She has no concept of it. And she's living her own nightmare with [certain aspects of her life], so maybe she's just not capable of seeing it. And.. I have to give her the benefit of the doubt on that, and.. let it go, 'cause I just get really angry. And it's just not worth it. I mean, she just can't deal with it, and whatever her reasons are for not dealing with it, she's going to have to come to terms with that. Nothing we can do. But it does, that does.. that infuriates--, or somebody, if they know of Alanna, and they make.. like non-existent reference to her, or they ignore her, then that really.. then I get my back up. You know, it's hard enough.. And I refuse to let my family intimidate me, I didn't care if they could handle it, I would talk about her. They were very uncomfortable and always changed the subject every time I'd bring it up. I'm very, you know, stubborn that way, it was just like, "No, you guys need to deal with this too. This is important to me, and so.. it's your problem, not mine."

Consequences of Disenfranchising Responses: Ultimately, the result of silences, platitudes, and loss-minimizing comments and actions on the part of parents' social networks was to complicate their meaning-making and cause them further emotional pain. Mona, for instance, recognized the lack of awareness behind a family member's hurtful comments, but she noted that it had long-term repercussions for her grief nonetheless:

She's done a lot of really nice things for us, but.. she's also.. done some very unusual things. And, you know, I don't think she's ever purposefully.. done anything to hurt us, but she's just done things without thinking, or said things without thinking.. the repercussion of it. You know, that it could have.. some kind of effect. And it *does*. You know, I... I'm sure it will bother me for a long, long time.

For some parents, the meaning-making repercussions involved questioning why they felt such intense grief if what occurred was not worth mentioning. As Penny indicated, the silence she encountered led her to question her sanity: "you've got all this pain, and no one wants to talk about it. And you feel like, you know, who really cared? [You end up thinking,] 'There's something wrong with me.'" Deena recalled having similar thoughts: "You wonder if there's something wrong with yourself, you know. You really wonder ah.. why.. you feel this way, and the others don't even think about it." For other parents, being told that their losses were insignificant translated into self-disenfranchisement – denying the significance themselves and burying their grief for many years. Sharon conveyed the "denial" she went through: "[I was] very much in denial sometimes. That it was a big thing. That is was a big thing, and that it should affect my life." Irene, too, denied the significance of her loss, viewing it as simply an "incident" in her life that was far less significant than the other losses and traumas she endured:

... the *other* things, the other.. instances surrounding the birth and the adoption of my daughter – I have let out and, and grieved before, but I'd never even talked about Keirin

before. Not much. Um.. thought of it as an incident in my life, but.. *never, never* examined it. *Never* took it out, *never* looked at it... Never *named* him 'till today, really, although I--, he had a name... And never wanted--, never.. well I don't know whether I wanted to or not, just somehow didn't {*emotion*}, and.. *couldn't*, I guess.

Some parents silenced themselves for fear of further negative actions or comments by others that would further disenfranchise their grief. Mona, for example, described her husband's reaction to negative responses of some members of their social network:

Like I guess at this one family reunion this summer, his grandma had the photo album there, and she was flipping through, and it's all pictures of her great-grandchildren. So she was going through, and then.. comes to this page, [a picture out at the cemetery, to represent Hannah as being one of her great-grandchildren]. And so she was showing people this, and he was *very* bothered by that. He said, "It *doesn't* bother me that she took a picture out at the cemetery. But it does bother me that she keeps that in.. a public.. type viewing that she shows everybody." And he said, "Because I don't want people talking about it.. all the time." You know, when we're not around. 'Cause.. he doesn't like to talk about it with anybody else but me. I guess because... he's seen some of the negative things that have been said and done, and.. he says it's better, then, just not to talk about it with anybody else. So... we *do* talk about it a lot. A lot.

Deena also did not talk about her son or her loss with others for fear of having someone say, "aghh, that's just so far away, why is she even thinking about that!" Christine too, found that she was silencing herself just 4 months after her daughter's death:

And I noticed *myself*, today, another new lady joined [the playgroup], and you know, she had a little girl, just a year old, and I remember thinking to myself, I wanted to tell her that {*emotion*} Dawn isn't my only one, you know, I've had another one, but I lost her, you know. I, I didn't tell her, but I kept *wanting* to. But I have a sense that people don't want to hear it anymore. {*said with great sadness*} You know like... it's the sense that people don't want to talk about it... it's uncomfortable for them to talk about it... and a lot of people think I should just be happy 'cause I have Dawn. You know, I have my, I have a girl.

Finally, Penny also felt silenced by the response of those around her, and she described her ultimate reaction to having her grief dismissed and ignored by others:

And I think that.. talk show I listened to, this one lady was saying, "You become so bitter. You become so angry at your husband, 'cause life goes on, and it seems that you're the only one that's carrying this memory, and no one else is. And no one seems to care." So, you do become bitter and very angry.. at everybody else. Along with all your grief.

#### *9.3.1.2.3 Instances of Support and Compassion*

*Be kind to yourself.*

*I'm so sorry.*

*If anyone in this family deserved a baby, it was you.*

*These were the most helpful and supportive things friends, family, co-workers, and acquaintances said to me after Jacob died. I'm not sure what my grief would be like today if I*

*hadn't experienced compassionate responses from the vast majority of people in my life. Not just sympathy, but clear messages that they recognized Jacob's death as the death of my child. No one told me to forget him. No one said, "Just try again." Yes, there were platitudes like, "It's for the best." But those were the exception. What influenced my grief the most were the positive encounters: friends who brought food, gifts, flowers, books on grieving for a baby; people who sent cards, attended the prayer service, made a point of conveying their sympathy even months later if we hadn't spoken since before his death; strangers who read the obituary and sent notes of sympathy and invitations to read their own stories of perinatal loss on the internet; friends and family who personally experienced the loss of a child and who reached out through a note, a visit, a phone call, or yearly e-mails on the anniversary day; family members who, without a word, placed a comforting hand on my shoulder at funerals or on mother's day, knowing how hard those occasions were for me; family members who asked my preference and then passed along gifts that were meant for Jacob, rather than assuming they should "protect" me by not mentioning them; people who spoke his name, months and years later; pregnant friends who asked about my pregnancy with Jacob, including me in conversations about pregnancy and childbirth; and those who never showed discomfort or changed the topic when I initiated conversations about Jacob and my grief, and took the risk of initiating the conversations themselves. These and many other encounters helped me to know that my loss has been acknowledged and that Jacob will not be forgotten. They helped me to grieve at my own pace and in my own way. And they helped me in my struggle to learn to live again, with peace and hope for the future.*



Most of the examples of supportive responses from social networks mentioned by parents pertained to the early days and weeks after their babies died. Friends and family members who showed grief and love for the babies around the time of death and burial touched some parents. Others mentioned their appreciation of family and friends helping with funeral arrangements and preparations, particularly gestures that added a personal touch (e.g., sewing a pillow for the coffin; making a grave marker), or assistance with tasks that were desired but emotionally wrenching for the parents to do on their own (e.g., helping to shop for an outfit for the baby to be buried in; assisting with building a coffin). Some with losses that were more recent commented on the overwhelming number of people who attended the funeral and conveyed their sympathy. These early gestures of sympathy and support were an important initial message to parents that their babies' deaths were acknowledged as losses. Those parents who did not have or were not included in funeral or memorial services (Andrew, Irene, and Penny) were deprived of the healing potential of the support offered on such occasions.

Those who were comfortable with the parents' grief, showed insight about loss, and displayed a willingness to talk and listen were important influences as parents grieved. Andrew found his insightful and compassionate listeners when he turned to his aboriginal cultural roots. Penny had a younger brother with "a lot of insight" with whom she felt safe and comfortable talking about her losses. Sometimes these sources of willing and insightful support were not family or close friends, but acquaintances or neighbours who happened, by chance, to be the

greatest comfort to parents. At times, parents noted their surprise that close friends were uncertain as to how to be supportive, while these acquaintances were quick to respond in a helpful manner. For instance, Rachel recalled that one of her greatest sources of support was from a neighbour who was a compassionate listener, rather than her close friends and family:

...There was one woman that I talked to the most, she was my next-door neighbour, and she had five kids and the oldest was about 10, so she was beyond childbearing years. And she could listen by the hour. Whereas all my other friends were either pregnant or waiting to be or just had a baby, and they didn't want to hear about it. So she was the one who listened the most. And she was a very.. just a wonderful, kind person too. Happened to be a good person to have next door. {soft laugh} So I talked to her by the hour. And she would just listen. Like she wouldn't.. ask a lot of questions, or... I mean, there was no point in placing blame, and that's what my mom wanted to do, was to blame somebody, you know, it had to be somebody's fault.

Another crucial source of support for some parents was other bereaved people. Many parents felt an affinity or kinship with others who had experienced loss and readily acknowledged the significance of the parents' losses. Dan and Stacie described their best friends, who suffered feelings of loss associated with fertility problems, as being particularly understanding and willing sounding boards for Dan's and Stacie's anger and pain. In other cases, mothers were helped greatly by other mothers bereaved of a baby, women who they were either friends with before or who they met through support groups. When the support came from another bereaved parent, the age of the deceased child was not an issue. Deena, for example, recalled feeling accepted as a fellow-bereaved mother when her step-daughter lost two teenage children and acknowledged Deena as someone who could understand her grief. An excerpt from Bill's story also illustrates the powerful unspoken kinship bereaved parents can feel for one another, and the resulting support they can offer one another:

[The parents of a boy Christine worked with were killed in a car accident]. The boy's grandfather came out with a food or flower basket... My initial reaction was "Get the hell out of here!" I **did not** want to see anybody. This was during the time that I was preparing her coffin. I was.. at that point, ready to be very aggressive. Until I knew who he was. And then everything changed. And he is a very gentle man. And was real-l-ly, really helpful. It wasn't that he did anything spectacular. It's just the fact that he'd been where I was, and could appreciate it, he had lost his son, just a month before. And, he knew that I didn't want to talk too much.

Sonya spoke of supportive actions by individuals in her social network that pertained to issues unique to perinatal loss, such as being around babies and pregnant women after her daughter's death. She recalled a close friend who responded sensitively to her difficulty meeting the new baby:

I got to meet her son, by myself with her, and cry. {begins crying} ...That kind of stuff.. And I guess for people who want to help, you know, that do have babies, and just



realize that babies are [such a sensitive issue] to somebody who's lost a baby. And just... you're happy for the person, but you're also.. sad for what you've lost and don't have. And just allow the person the ability to.. cry when you're with the baby, and that really helps, it really did.

Mona, too, mentioned a supportive gesture by a friend who had a baby shortly after Mona's daughter died. While perhaps not something that every bereaved mother would find helpful, this example illustrates the importance of social networks openly addressing the issue.

...the first hockey game I went back to was unbelievable. All the wives of the hockey team players, they were all just wonderful. They sat with me and wanted to talk. The one girl had had a baby [about a month before], and she came over to me, and she said, "Here. Hold him." And I immediately, like I, I was sweating, I was.. all flush, I.. I felt like I couldn't breath, and I said, "No! I can't!" She says, "No. Hold him." She says, "Hold him for the whole game if you want, but you hold him." And oh-h, that was *really* hard. Very, very hard. But I'm glad I did it, very! Very glad she did it. Because... she made me stop and realise that life does go on, and.. she was there to support me. She wasn't doing that to be mean. She was doing it because she was saying.. this is what you have to do, you have to get on with your life, you have to talk about it, you have to be around other people... It was very.. weird, but she also knew that so many people around me were having babies, that if I didn't do it *then*, that when I *did* finally hold one, it might be harder in the long run.

Mona's contrasting of two pregnant friends' responses after her baby's death further illustrates how helpful an open approach was with respect to the topic of pregnancy:

...my one close friend was *very* unsure about being around me when she was pregnant – I think because she was scared... if she talked about what happened, that it might happen to *her*... Whereas this friend, she never pretends like nothing happened. She talks about it non-stop. She *constantly* calls me and says, "When you were pregnant with Hannah or Jasmine, did you go through this, and~" [She didn't ignore my pregnancy with Hannah]. It's good. It's very helpful that way. Very helpful.

Concerning the response of employers and co-workers, a number of parents experienced compassionate support in a variety of ways. Some spoke of co-workers who were willing and comfortable with conveying sympathy openly and taking the time to listen to parents talk about the death and their grief. Bill described the assistance he received from his employers and co-workers when he was building his daughter's coffin, and his astonishment at how many co-workers and their spouses attended the funeral. Others commented that employers were supportive by permitting a longer bereavement leave or being flexible in granting time off when parents needed it. Katrina noted that she was still able to take maternity leave and a 15-week sick leave after her daughter's stillbirth. In contrast to Judi's experience in 1976 (i.e., no bereavement time or maternity leave granted), the social institutional changes in place by 2001 gave Katrina time to grieve in the way she needed to: "It's nice to have that time to yourself. 'Cause I wouldn't have wanted to be around anybody."



Beyond the initial period of grief, parents' meaning-making was facilitated by comments and gestures that showed them that others were not forgetting their babies, such as initiating conversations and sending cards to acknowledge anniversary days, or displaying a willingness to mention the babies' names during everyday conversation. Some family members' actions or remarks that acknowledged the babies made parents uncomfortable, but they recognized the actions were rooted in supportive intentions. Penny, for example, recalled her mother's way of remembering her deceased grandchildren:

My mom will say.. she'll tell people.. that she has a lot of grandchildren. And then, [one of my brothers] lost a baby boy, full term. And she'll say, "I have," this many grandchildren, and she'll say, "I have four angels in heaven." So she'll often.. she'll say it. And sometimes it bothers me, but I guess... She introduces me to someone, she says, "Oh, this is my twin, she has 4 kids, and she lost 3 babies." {makes an amused, taken-aback face} You know, sometimes it kind of bothered me, but now I.. it doesn't, I think it's her way of acknowledging it, too, you know. She comes from that type of generation too, like I said, they never talked about things, so it's hard for them too.

### 9.3.2 Common Meaning-Making Strategies

The meaning-making influences discussed above originated as external influences that impinged on or facilitated parents' attempts to make sense of their experiences of perinatal loss. In contrast to these external influences, "meaning-making strategies" implies an internal pursuit of meaning on the part of parents. This is not to say that parents were always *conscious* of using meaning-making strategies, but that the process came about internally, rather than being an external influence that was not under the parents' control (like a family member's loss-minimizing comments)<sup>28</sup>. While not a comprehensive treatment of the meaning-making strategies adopted by parents, the following subsections are exemplars of the most common strategies used.

#### 9.3.2.1 Finding and Making Meaning through Spirituality and Religious Beliefs

*I'm sick of trying to be positive about what grief can do to a person. Yes, I feel I've changed. Yes, I feel more mature, wiser; but I also feel sorry for myself. I also get so angry about things, both justified and stupid things to get angry about. I keep looking for answers from God. How does he work? Does he intervene? If he does, why didn't he intervene for me? I've just finished reading a book that outlines a different, non-literal way of reading the bible. It appeals to me because it lets God off the hook again. He doesn't intervene in the way implied by those who pray fervently for specific assistance, for rain, for healing an ill relative. I don't think I'll ever be*

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<sup>28</sup> Note that external influences were *not* under parents' control in the sense that the comments and actions of others occurred regardless of how parents responded. On the other hand, parents *did* have control in the sense of being able to consciously resist the negative influence that such actions or comments had on the meanings they derived from their experiences. Note, too, that meaning-making influences can be internal as well as external, as in the case of personality traits or self-esteem difficulties affecting how a person makes sense of their experiences. These influences, however, are more conducive to individual consideration as in the previous discussion of personal meanings in the five stories, rather than in a discussion of common themes seen across individuals.

*fully satisfied with the answers I get about God. But I've got to try to understand. I know that Jacob's okay where he is, but somehow I'm far more interested in the afterlife than I was before. (Journal entry, May 2002)*

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A few of the parents did not spontaneously mention looking to spirituality for answers or comfort in their grief, but whether they were asked or they addressed it on their own, all had definite opinions and had clearly given the issue some thought. The majority viewed spirituality as a notable means of trying to make sense of their losses at one time or another as they grieved over the years. For some, spiritual meaning-making presented obstacles to be grappled with, and ultimately proved to frustrate their efforts to make sense of their loss and grief; for others, this strategy was essential in giving them meanings that brought comfort and peace.

Anger, Confusion, and Persecution: A number of parents spoke of anger at God for allowing their babies to die. Although recognizing that the belief systems they ascribed to provided some answers in this regard, they were either unable to reconcile their beliefs with their losses and pain, or were unconcerned about doing so. In Luke's case, he conveyed the guilt he felt for being angry with God:

I feel bad for that part. Like I really... stopped praying. Like I always prayed to God before she was born that everything would be alright. And then when that happened~... I shouldn't be [angry at God], but I guess I am. I know it wasn't His fault, and.. when the priest came over, he made it a little easier. He said God doesn't plan for babies to die. Like people make remarks and stuff. I mean, what God would ever want.. a baby to die.. before it was born. There's just no way that happens. But no, I don't even make any secret of it at work. Like whether I should say it or not. I just tell them I don't believe in God. And I don't mean it. It's because I'm so mad. It, it's funny how you.. blame God for things when they go wrong.

Other parents noted their anger at God and their inability to understand why God would allow babies to die, but did not view their spiritual beliefs as a particularly significant part of their experience. Sonya, who described herself as "not overly religious" but having a belief in God, illustrated this as she discussed her belief that her daughter is in heaven:

...she's got to be there, 'cause that's the safest place for her to be... I haven't gotten back to religion. I still have a hard time thinking how a benevolent God can do something like this to such a helpless little baby. And wondering, well am I such a horrible person that God would want to do this to me. And those kinds of thoughts. But you're realizing that's.. I mean, if you're a true Catholic you know that's not the way it works... I haven't found any consolation or any great support from it. The priest was actually not bad, I mean he came up to the house and... I was ready to pick a fight with him, it was sort of like, "God did this, and how could he do this?" And he actually defused me by saying, "It's okay to be angry with God." And it was like, "Well you're no fun." {laughter} "I'm angry, I want to~" {laugh} But really, [spirituality has played] not a significant role at all.

A different but related meaning derived through the spiritual beliefs of some parents was the feeling of being persecuted or tested by God. Christine, who held strong Christian beliefs, felt she had experienced more than her share of death and felt like she was being persecuted for some reason.

Death has been one of the things that have kind of plagued me my whole life. Lots of death in my family. [Having so much experience with death] makes me more mad at God, in that I think, "Enough already!" But then, the other part of me thinks, well, we're all going to die anyways, like I know that life is only.. temporary. So-o-o {sigh} I don't know.. it's just that ah.... sometimes I could feel persecuted? I, it's funny, I think.. different people have different crosses to bear in life, some people it's illness, and me.. it just seems to be losses, like I just *lose* people that I care about a lot, you know, just one of those.. things. But then, {sounding more cheerful, optimistic} I never thought I would be able to get married and have Dawn at least. That's the other side of it, I seem to be very lucky in that.

In a strikingly similar way to Christine, Judi spoke of death following her "like a black panther" because of the number of loved ones who had died in addition to her son. The feeling of injustice she had over being a childless mother and experiencing so many losses and life difficulties prompted her to look to God and her mainline Christian beliefs for a reason for it all. She wondered what she had to prove; she felt God abandoned her; and she tried to understand why God repeatedly offered the happiness of a child and then kept "yanking it away." Her conclusion was that God was punishing or testing her. Since she was unable to find comforting or forgiving answers through her spiritual beliefs, and unlike Christine, was denied a chance at motherhood, she fell back on shame and self-hate for her perceived role in her son's death.

Irene's and Mona's stories illustrate another side to this struggle to make sense of loss through spirituality and religion. They did not speak of anger per se, but of a painful confusion about why such tragedies occur. Mona spoke of going through a questioning process in an attempt to understand why God allows babies to die:

...in the back of my mind, I'm always thinking, you know, why? Why would a person [God].. do that? And then I see things on TV.. you know, like TLC is constantly showing the labour and delivery, and they'll have some.. crack addict having a baby. And I think, why would a God.. allow *that*, but yet *not* allow.. wonderful people that Trent and I *think* we are, {laugh}.. be allowed to have a healthy happy baby... So I guess, in some ways, it's made me realise, more, that there has to be a reason for everything happening, there.. there is a God, and there is a reason why he's doing stuff. But then in other respects too, I think.. well, if there is a God, why.. you know, what kind of God is he, that he does this to people?... I've questioned a lot.

Irene engaged in a similar questioning process, and over the course of her many losses and traumas she eventually came to reconstruct her spiritual views while keeping within her mainline Christian tradition. This reconstruction was a part of her overall transformation of self and her

reconstruction of the meanings she ascribed to her life experiences. The following excerpts provide a glimpse of her poignant, hard-won new spiritual philosophy:

And you think *why*. You know, you always ask why. I'm sure you've asked *God* why. [I haven't dealt with that side of it] at all, I suppose, because I didn't.. acknowledge it [the death of her baby]. But.. in the other things that I have dealt with, I've realised that not *always* do I know.. do we know why. And not always *is* there an explanation. But there is some kernel of positivity in everything.. bad. Even if it's to be helpful to somebody else, in a way. And then.. people pray and they want an answer to a prayer. I've realised that sometimes, no answer is an answer. You know, that is an answer in and of itself. And the fact that I am here, and the fact that I am... reasonably healthy, {laugh} and well, and still able to give, is.. that's who I am. *All* of these things that happened are, are.. who I am... I don't mean "meant to be," I don't mean that, ah.. so easy, or so blanket~ But that I wouldn't be me, the me I am, if that didn't happen.

[What has helped me in recent years is] finding my spiritual self... I have great faith... When I talk about my faith and my spirituality, I can be just as, as comfortable out there [in my garden], than I can in the church. You know, it's just the same to me. It's, I think it's.. your own inner stillness that's~ ...I'm *supposed* to [believe in an afterlife, in heaven], 'cause I'm a Catholic. I'm *supposed* to 'cause I'm a Christian. And there's days I do. But you know, I really don't. Except, I *do* believe in love. I do believe, if there *is* a God.. I believe in love, in God being love. And ah.. so I believe in a gentler, happier place, if there is a place it's a gentler, happier and loving~ And I think I believe *that*, more than anything else, that ah.. I don't believe there's nothing. And I think it's just a sense of being. My feeling is a sense of being, a sense of.. of love. Of love being personified in some way.. because love is all things, I think. Like that there's no hunger, there's no thirst, there's no pain, there's no anger, there's no.. grief. There's just love.

Centrality of Beliefs to Well-being: Some parents indicated their spiritual beliefs were helpful or central to their well-being. Andrew, for example, found that the aboriginal culture spiritual tradition does not criticize or judge for past mistakes, and he credited it with helping him give meaning to his experience and support him in his grief. He emphasized that he was no longer Christian (Roman Catholic), a belief system which he viewed as lacking in support and being judgmental, especially of young men in the situation he was in (teen pregnancy, drug and alcohol problems). He found the support of his culture's spiritual teachings and traditions more fitting than any counselling he might have received within what he viewed as the more detached western model of treatment and therapy. In contrast to Andrew's experience of Christianity being judgmental and unsupportive, Bill emphasized that his Christian beliefs were crucial to giving meaning to his experience:

For us, it's really two things that are the most important things, is our religious values, and our church participation. And, secondly, there's Dawn. It's not just Christine and me, it's Dawn too. It's all of us together. And the two are really very closely related, to my way of thinking especially, ah.. family is nothing without church, the religion that we both ascribe to. And ah, {sigh}.. religion is something that all of us need, to explain all the bad behaviour, all the good things that happen in life and how they happen. It gives meaning

to all of it. Without that belief system in place it has little meaning. And, in most cases I can see it being much easier for couples to break up after something as devastating as the loss of a child.

While strong religious beliefs were comforting for those parents who held them, the associated promise of peace was more elusive for some parents than others. Deena's Christian faith helped her in her attempts to ascribe a reason or purpose behind her son's death and the two miscarriages that followed. The meanings derived from her faith appeared to give her some comfort that God knew more than she did, that there must have been a good reason which only God knows, and that her son is with God. But the peace she felt was not complete, and why she was not allowed to keep even one child of her own remained a painful and unanswerable question for her. In contrast to Deena's ongoing struggle to find peace, Rachel spoke of a more complete peace that came about through her Christian beliefs.

I think so much depends on your outlook on life... I believe God will never give you more in your life than you can handle. You know, like I said when I couldn't imagine.. surviving.. walking out without a baby.. when it happened I could handle it... He gives you the strength. And when I think back, I don't know if I accepted it quite that easily at the time. But overall, in the long run, that's how it~ I know I feel more that way now than I did when I was younger, that things just are the way they are, and there's nothing you can do about it, you know. And.. don't worry about anything you can't change. So if you can't bring him back or change anything, then you just deal with it. Not that you forget about it, or.. you deal with it the best you can and get on with life. So I guess that's my philosophy {soft laugh}

While Deena voiced a very similar philosophy and adhered to the same belief system as Rachel, perhaps her inability to have other children contributed to her difficulty finding peace through her beliefs. The meaning childlessness had for someone of her generation may have complicated her meaning-making to such an extent that her religious meanings were overshadowed. That is, Deena was from a generation that placed value on a woman's sole focus being her husband and children. When her motherhood was thwarted, she may have come to view herself as a failed woman, a meaning which was difficult for even strong religious beliefs to overcome.

A Spiritual Presence: A number of parents spontaneously mentioned an awareness of the spiritual presence of their babies, or of a spiritual being taking their baby at the time of death. Dan and Stacie had a clear awareness of their daughter existing in a spiritual sense, referring to her as their guardian angel. Andrew had a similar feeling about his daughter, and had experienced a number of specific examples of spiritual communication with his daughter, including being given her name in a dream. Given her Christian beliefs at the time, Sharon perceived the spiritual presence that she felt at the time of Tasha's death as being Jesus. She stated that this feeling had left her, and she did not understand why but wished she could feel it

again. As discussed previously, a sense of spiritual communication with her daughter was something Sharon longed for, but she believed she had not had such an experience because she had “abandoned” Tasha before her death. Judi’s feeling of her son’s presence was utterly negative, based on her view that she was being punished for having failed to protect him. In contrast, Mona’s interpretation of occurrences she and her family had experienced provided her with a comforting feeling of her daughter watching over them. The excerpt below provides a unique example of the spiritual meaning-making that couples and families engage in to give meaning to a baby’s continued existence after death:

And as our minister was saying, “Ashes to ashes, dust to dust,” a raven flew over.. and squawked. And I noticed it right away, because we’re very outdoorsy people, we’re very much into nature, and.. I just, I thought.. well that’s.. poignant, that’s.. something neat. And I didn’t look around at anybody else to see if anybody else noticed. But as soon as we got in the car, Trent looked at me and he said, “Did you hear that?” I said, “Yeah, I did.” And he said, “You know, when we get home, I’m looking that up in my book.” He likes to read a lot about native history. And he *knew* he had read, in one of his books, that that was symbolic of something. And we got back to the house.. my dad came up to me right away. And he said, “So? Did you see that raven that flew over? That’s.. you guys, that’s something for you!” And, so Trent looked it up. And it did say in there, like there’s a few different meanings, for ravens, but one of them is that it’s a leader, and in death it will stay around your family. And so we thought, you know, that’s pretty neat... And so many things have happened in the last year with a raven, that it really does mean a lot. We had never had a raven nest in our trees... And last spring, in March, a raven built a nest in one of those trees. And it makes a lot of noise, but it’s there! And to us, that’s Hannah. That’s.. that’s her soul. Living there, protecting us, keeping her eye on us. And every time we go out for a drive now, we always watch. And you see ravens and crows everywhere, but.. it’s just something that comforts both of us. You know, and it seems like every time we go out to the cemetery there’s one out there that flies over and makes a bunch of noise. Which.. to *us*, it’s special. To some people, you know, we told people about it, and some people would look at us like, “Well that’s.. kind of weird.” You know.. but to us, it meant a lot.

#### 9.3.2.2 Finding Meaning Through Comparing Losses: Who Hurts More?

*“Don’t you ever get tired of hearing about someone else we know getting pregnant or having a baby?” I reach over to the bedside table, searching for a book to read before going to sleep. My husband has just commented that a number of acquaintances’ and friends’ babies are due in the same month this year. “Sometimes it’s hard not to be bitter and jealous.”*

*“It could be worse.” He says this matter-of-factly with no elaboration.*

*“Really?” My doubt is audible in my tone of voice. I think, “Oh boy, here we go. He’s minimizing what we’ve been through again.”*

*“We could be like Bill and Jane, not being able to have kids at all.” It sounds as though he’s thought about this a lot.*

*“Are you saying infertility is worse than what we’ve gone through?!” I search his face, incredulous, a sick, angry, despairing feeling rising in my chest. “Please don’t say Jacob’s death and all that followed was easier than being faced with infertility,” I silently will him to agree with me. In the back of my mind, I’m surprised at my reaction and the passion behind my words, given my frequent complaint about people rank ordering the degrees of pain brought on by*



different types of losses. I feel a twinge of guilt, but the surge of anger and grief is stronger, and what started as an innocent enough discussion turns into a pivotal moment in our ongoing struggle to respect one another's way of grieving.

"It's time to get over it!" He's suddenly frustrated, impatient. I recoil at his words, fearing that the worst has been confirmed: he thinks I should be "over" Jacob by now. Is that what he means?

"Get over what?!" I retort angrily, hoping against hope that my first assumption is wrong.

"Get over being bitter."

I consider this, feeling some relief, but the blazing anger can't be extinguished that easily. "Besides," I think to myself, "I have every right to be bitter from time to time, especially since I've been trying so damn hard for the past 2 ½ years to not be bitter and hateful. Doesn't he know how hard I've been trying? He would if he had read any of my research writing or Jacob's web page." This thought adds fuel to my burning anger, and I suddenly feel like I need to leave the room. "I'm not bitter!" I say, feeling my blood pressure rise. "And even if I am, I have every right to be bitter now and then! I have tried really hard not to be bitter! If you want to see bitter, there are some people who refuse to hold a baby and hate being around kids, even 5, 10, 30 years after their baby dies!"

I turn my back on him and turn off my light in anger. "He doesn't have a clue what I've been going through! How can he be so damn positive, as if what we've gone through was nothing?!" I wait for him to apologize, to say something, anything that will cool my anger and let me know he is still grieving too. The seconds tick by in silence. I jump up from the bed and stomp out of the room. I have no intention of sleeping in our room tonight. "Let him make the next move," I think angrily.

I lie in the spare bed in what would have been Jacob's room, waiting for him to follow me so we can talk this through. Knowing my behaviour is immature, I consider going back, but I know I will just blast him with more of my anger. I fight back angry tears, pull out a sheet of paper and a pen from the bedside table, and write ferociously:

He doesn't even care enough to read any of my work, or look at any of Jacob's mementos that I've put together, or even to read the family letter that I wrote on the 1<sup>st</sup> anniversary. How can he say infertility is worse than what we've gone through? Why can't he say that it all sucks? Why does one have to be worse than the other? But if he insists on rank ordering, how can he say that infertility is worse than losing our child? How dare he? And why can't I be bitter from time to time? I've tried to be Ms. Mary Sunshine for so long, and sometimes I just need to vent my continuing frustration at having to hold off on having more children – a situation that I've created through hanging on to this bloody Ph.D. And even if it wasn't for that, why can't I be a little sick of hearing of everyone we have anything to do with getting pregnant and having beautiful, healthy, live babies? I don't wish the worst on anyone, but that doesn't stop me from feeling sorrow and jealousy every time I know that someone else gets to hold a baby in their arms to call their own.

I push aside the pen and paper and allow the tears to come. My anger is spent for the moment, and the underlying pain and bitterness pour out. I know that we will patch things up in the morning, and as I cry myself to sleep, I pray that neither of us dies before then.

I awaken to him kissing me on the forehead, and as I roll over he wonders aloud, sheepishly, if I still hate him. I relent, and we are soon talking about our fight.

"I don't like it when people rank order painful experiences. Why does there have to be a hierarchy? It's all painful, can't we just leave it at that? But for me, losing Jacob was far worse than the prospect of us not being able to have more of our own children. I would gladly adopt children." I am surprisingly calm, the anger replaced by a keen desire to understand what he's thinking.



*"Would you rather have had Jacob as we did, or never have had the chance to have him?" Suddenly a vaguely familiar feeling arises – one that I've felt on other occasions when it has become clearer to me how he feels and thinks about Jacob. "I guess if I had a choice of having Jacob and having him die versus not having him at all, I definitely would want to have him. I'm glad I got the chance to go through pregnancy and childbirth, and I'd rather grieve over Jacob the rest of my life than not have had him at all."*

*"Well, a couple who is infertile doesn't even get that chance."*

*As we talk more, it is clear to me that he, too, was glad that we had the chance to experience being parents to our son even as little as we did. And as painful as it was to lose Jacob, he would not trade our tragic experience with that of an infertile couple, because that would mean never having a child to love at all. Once again, I have made assumptions about his feelings based on a misunderstanding, and once again he has surprised me, and relieved me, with what his true feelings are. And I am reminded, once again, that he grieves differently than me, but he still grieves.*



This episode from my personal experience illustrates a couple of things. First, it touches on some of the hurdles a couple faces because of coming to different meanings in their struggle to make sense of their loss, as well as grieving on different "schedules". Second, it speaks to the possibility of conflict because of the common tendency for men and women to grieve in very different ways (e.g., Wing, Clance, Burge-Callaway & Amrinstead, 2001). Finally, and the reason I have included this example here, it shows how perinatal loss led to what was a prevalent strategy that many of the parents (and their social networks) used to find meaning. Specifically, many parents compared their perinatal losses to other losses in a hierarchical way, as though trying to determine or demonstrate how much pain they were feeling (or could allow themselves to feel) in comparison to other bereaved persons.

Comparing different types or circumstances of losses appears to be intrinsic to society's way of making sense of death and grief in general, and, being members of society, bereaved persons adopt it as a strategy as well. Nadeau's (1998) study found that such social comparisons<sup>29</sup> were the most common meaning-making strategy used by the bereaved families she interviewed. For example, participants compared the current death with other deaths, both inside and outside the family, with the usual pattern being that deaths of younger family members were deemed to be more difficult to bear than deaths of older people. As well, comparisons took either positive or negative forms; positive comparisons suggested that someone else's bad fortune was worse in comparison with their own, and negative comparisons led them to conclude that their experience was worse than the losses of others.

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<sup>29</sup> Social psychologists have postulated that downward social comparisons are a means of coping with negative life events (e.g., Wills, 1987).

The hierarchical or rank ordering of types of losses as a way of making sense of death seems to be an inherent part of the grief over the loss of a child at the perinatal end of the age continuum, in contrast to the grief of parents bereaved of an older child. When an older child dies, there is almost universal agreement that it is more difficult than other types of bereavement (e.g., Cleiren, 1993). I would argue that for those parents, there is no need for engaging in such comparisons, because the magnitude of the loss is fully accepted by the parents and everyone around them. Among the parents that I interviewed, some responded by minimising their loss in comparison to others, while others responded by saying their losses were the worst they could imagine, or worse than their own previous losses. The fundamental difference between these parents and those who lose an older child lies in the fact that a perinatal death is a disenfranchised loss. Because it is not a socially recognized death in the same way as the death of an older child, parents are compelled to make sense of their loss and their grief by comparing themselves to other bereaved people. They follow the lead of *or* react against covert societal messages and explicit messages from those in their social networks who minimize what they are going through.

“They seem to think it’s easier”: As indicated in the above discussion of disenfranchised grief (section 9.3.1.2.2), many of the parents were subjected to loss-minimizing comments from members of their social networks. Such comments included comparisons to other types of losses or other circumstances that implied that what these parents experienced was not as difficult. Regardless of the intended message of the speaker, parents’ perceptions or the meanings they derived from what was said or implied were most relevant for their grief. For example, Sharon explained her perception of a comment made to her at a funeral, and although she was uncertain that she interpreted the comment correctly, her interpretation was what had an impact on how she grieved.

I was at a funeral of a relative who died, and I was saying something to her children, they were in their early 20s.. I was saying something about how I know grief, and I know what it was like when I lost the baby. And their father said, “Yeah, but this is different. Because..” ..it was *almost* as if he was saying, I can’t remember what he said, that’s *all* he might have said, “But this is different.” With a sense of, “Well, she was just a.. mutant kid.. that wasn’t.. you know, this was my wife here, who I loved for 25 years. And yours was just a defective kid.” That was the *feeling* that I got. Maybe he didn’t mean it that way, but that was the feeling that I got. That’s why.. I often.. feel like I can’t share this with anybody, because.. I feel that that *feeling* will come from people.

At one point in my own experience, I concluded from the research I did and the personal social interactions I had that most other people I encountered would rank my loss lower on the loss

hierarchy than any other loss. This conclusion had a bearing on my willingness to share my grief with others:

At every turn, I hear or read about someone minimizing the intensity of grief over a perinatal death. Researchers speaking of parental bereavement often suggest perinatal loss is less intense and easier to bear than the loss of an older child. Even when it is not explicit, I find myself assuming or suspecting that people see it that way. Not just in comparison to other bereaved parents, but other forms of bereavement as well. I often feel that many people don't see my loss as being as significant as the loss of a spouse, a parent, a sibling... in other words, not as significant as the loss of **any** living person whose personality and individual qualities were known by others. Anyone who had relationships with people - unlike a stillborn baby or an infant that died before anyone got to know him/her. This is why I don't feel like I fit in at TCF meetings. (Journal entry, May 2001)

Through their experiences, both Sonya and Luke also expressed their observations that perinatal loss was viewed by others as lower on the grief hierarchy than other losses:

...people do try to make magnitudes of what your grief is, and I think that's why some people have a hard time with stillborns or very early infant deaths in terms of.. the fact that.. they seem to think that it's easier, and they don't understand that you're grieving for.. what you've lost, in terms of.. you know, not being able to see her.. grow up, and her first Christmas and her first birthday, and.. all of the anniversaries, and I mean.. even with this baby [current pregnancy] it's just like, I wouldn't have time to be so tired, because I'd be running after her, and I wouldn't have time to be fretting as well. You know, and that kind of stuff. (Sonya)

...in our family I think [expressions of sympathy] would be more likely if it was someone that was living. That's the feeling that I get. [They wouldn't expect us to get over it so fast.] I think it's because no one knew this.. little girl, that they figure it should be~.. it's sad, but I think if it was someone living for even a month, a week... you know, a half-a-year, a baby, I think people would be more apt to say something... It's sad. I don't know what you feel, but that's what it sure seems like to me. (Luke)

"It's got to be much harder if.." Some parents' comparisons of their experiences to others' losses led them to conclude that different circumstances would have made their losses worse. In a sense, they were minimizing their grief; but they were not saying their losses were insignificant, only that as difficult as their grief was, it might have been even worse. Christine, for example, spoke of her belief that her husband's grief would have been even more difficult to bear if their baby had been a boy:

...the fact it was a little girl, that's the part, I mean, this.. might hurt my husband if he knew this, but, he wanted a boy so bad, and because the pregnancy was so different I thought it was a boy, I kind of felt, I thought oh, jeez, you know, it might, it will be his son, and oh, won't it be nice. When.. the baby didn't make it, one of the thoughts I had was, well I'm glad it was a girl. Because I think if it would have been a boy it would have *killed* my husband.

Like Christine, Luke considered the circumstances that would have made a loss such as his even more difficult:

And I felt so bad, because I know for a fact someone had just lost a baby just before Christmas, because the grave was fresh there. With the wood just over it. I said, "Oh my God." It was bad for us, but can you imagine losing.. whoever did, lost a baby just before Christmas or whatever, because it was all.. the dirt was still there.

As mentioned previously, some fathers also minimized their grief in comparison to their wives' grief. Other parents, like Mona, speculated that the loss of a baby was less difficult than the loss of an older child. While not wanting others to minimize her loss, her placement of her own loss lower on the grief continuum than the loss of an older child led her to avoid attending a support group for bereaved parents. Her explanation illustrates the complexity and contradictions inherent in trying to determine where one's grief should be placed on the loss hierarchy.

...for the first few months, I *wanted* to [attend a meeting].. but... we also never did, we never went... 'cause I don't know, I felt like... I, I didn't want to go to something where.. if somebody else was going through something more difficult than me, I didn't want to take away from that... 'cause I *know* it's got to be *much* harder if somebody loses a child that's older... Growing up, I had a few friends that were killed in car accidents when they were teens, and I look at their parents and I think, yeah, they've lost a child, we've lost a child, but they bonded with that child for 17 years before they passed, it must be much harder. And I thought, I didn't want to go [to a meeting] and then to come out of it feeling like I didn't belong. Or I didn't deserve to have the same kind of feeling that they did... I felt like I would have to.. not tell the whole story, because somebody might look at me and think, "Well! It couldn't have been that bad, because you weren't around the baby for that long."

"Even more of a tragedy": In an attempt to establish the profound significance of their losses, some parents elevated their experience of perinatal loss on the grief hierarchy in comparison to other forms of loss, including that of other bereaved parents. This strategy appeared to work toward emphasizing the great impact of their babies' deaths. Judi and Dan, for example, both spoke of feeling that the deaths of their babies were worse than other deaths, including the death of an older child, because of the absence of memories of the baby's life and being denied the opportunity to form any happy memories. Luke, too, imagined that he would never experience a worse loss:

I can honestly say... out of all the deaths, I don't think there'll ever be a worse one than that. And I haven't even had my parents die. I can't even imagine my parents dying.. me taking this long.. of being so mad... [Katrina] said this was way worse than her dad dying. I can't say that, 'cause I haven't gone through it... But for us it was the worst darn thing. It would have to rank right up there. And I, you know what, it's funny... a lot of people don't understand why there'd be any pain at all. And I really think that's how some people think. Because.. the baby was never here. And it's sad... they're just terrible.

Sonya considered her grief over her daughter's death in comparison to her grief over her mother's recent death, and concluded that being a bereaved mother involved more intense grief than losing a parent:

...and then my mom got sick, it's been a real.. year from hell, and she died in January. And so um.. it's funny, because the grief process for my mom.. is nowhere as intense as the grief process for my daughter. I, I feel almost guilty, but it's just.. not the same kind of.. loss. It's a loss, but it's on a totally different level, it's just.. maybe I haven't processed it fully, which I probably haven't, 'cause I'm dealing with a lot of different things. [including a subsequent pregnancy]

Parents who had experienced both miscarriage and perinatal loss, while acknowledging the feelings of loss associated with miscarriage, emphasized that the loss of a baby through stillbirth or neonatal death was far more difficult for them. As Mona illustrated, having others equate her perinatal loss with miscarriage on the grief hierarchy triggered her anger at what she felt was a minimizing of her loss:

I even had one lady who called me.. I know her to see her around, but we're not close friends. And she called and said, "Well I know exactly what you're going through. I had a miscarriage when I was just 5 weeks. I didn't even know I was pregnant. I went to the hospital because my period was hurting me more than normal." ...and she was crying, and I thought to myself, yeah, she has pain over this, but.. it's *not* the same... I did get angry, and I said, "Please don't compare. Because what you went through was *nothing* what I went through." I said, "Thank you very much for calling, but... it's much different, and I'm not ready to talk about it." 'Cause she called me about a week after [my baby died] and said that and I.. it made me *very* angry, I thought, "Don't minimize what I went through." {soft laugh} Yes, what you went through was tough, but like you said in your own words, you didn't even *know* you were pregnant... Like I had gone through a very similar [miscarriage] to her, and it's *very* different. *Very*. You know, yes, it all hurts, but~

Other parents did not elevate their losses on the grief hierarchy, but equated them with other losses, like the loss of an older child. Owen, for example, spoke of this poignantly when discussing whether he and Sonya considered themselves to be parents:

I consider that Sonya's not just a mother but {sobbing, whispering} a very.. very good.. .. And ah.. the way I look at it is.. ah... just looking at Sonya as a mother.. and.. {breaths out loudly, crying throughout} ...she's certainly missed out on the joys and all that kind of stuff of.. had Alanna lived. Ah.. she missed out on.. all the trials and tribulations as well, had Alanna lived, the late nights and the colicky baby and the worrying and the falls and all these sorts of things. So she missed out on those "bad things," if you will. But she had to go through probably the worst thing that any parent could ever do. {voice breaks, crying as he whispers these last words} And, and ah.. Like it's something that no parent should have to do, is bury their own child. And ah... whether the baby's an hour old, or 20 years old or 40 years old. A parent should never have to bury their own child... {whispered, crying}

Perhaps for some parents, as an excerpt from my personal journal illustrates, the strategy of magnifying or equating their perinatal losses with other losses speaks again to the desire to have one's loss recognized as painful and significant.

"I don't think you get over it, but you learn to live with it better." This is what my husband's grandmother, whose son died of a heart attack in his 50s, said during a group conversation in which someone brought up Jacob's death. Her comment in that context helped me to feel included in the bereaved parent "group". For all of my talk of not wanting to compare types of bereavement in a hierarchy-of-pain way, I certainly do seem to want someone to agree with me that perinatal loss is just as bad as the death of an older child – I want "one of them" to tell me this. It's not good enough that others *like me* agree with me; I also want validation from bereaved parents who've lost an older child. I want recognition for the severity of my grief and the massive significance of my loss. Like Sharon, I don't want to hear, "Yeah, but this is different." (Journal entry, June 2002)

"You can't weigh pain": In contrast to the instances of comparing losses on the grief hierarchy, other parents voiced their conviction that losses cannot be compared because every loss involves emotional pain, despite involving different challenges. Katrina voiced this concisely by saying, "Anything's terrible" in response to Luke's attempt to rank-order various types of perinatal loss. In my personal journal, I expressed my frustration with the hierarchical comparisons of loss, being unable to comprehend why the bereaved and those around us resort to this strategy.

Why do we have this need to rank-order things in terms of least to most difficult? Especially when talking about death and loss. It's like trying to say, "Your hell isn't as bad as mine." What's the point of this? To say, "You suffered less than me, my pain is greater than yours; my loss is worse, more significant than yours..." Why do we do this?!! Is it a matter of trying to say, "I deserve more sympathy than you, more lenience, more time to grieve, more understanding if I'm not back to 'normal' as soon..." (Journal entry, May 2001)

Regarding the comparison between perinatal loss and the loss of an older child, Sharon highlighted the unique challenges brought about by these different losses rather than seeing her baby's death as more or less significant. Her decision not to attend a Compassionate Friends (TCF) support group came about because of these differences, rather than being about the belief that her loss was, or would be viewed by other parents, as lower on the grief hierarchy:

...even though I felt a kinship, there was still a sense of.. it's not the same thing. It's different, because there are issues of pregnancy here that I can't discuss, there are issues about my milk coming in that I can't discuss... The thing that hit me [when reading the TCF newsletter], is so many of them talked about the memories, and they had a lot of memories with these children, and all I had was.. a hard, very hard memory. And then.. just hopes and dreams and.. thoughts.



Finally, Penny's experience of multiple perinatal losses prompted her to accept all forms of bereavement as being painful, and she spoke passionately about her view that losses should never be compared or minimized.

...you tend to downplay what you've gone through, saying, "Well I guess it wasn't that bad." 'Cause you have people.. one of my sister's is really bad for that, she'll go, "Well you know, I know it was bad, but don't you think it would have been a lot worse if they would have lived, like a year, and then they would have died." And that used to really bother me... I used to say, "Situations might be more severe than the next. But you can't weigh pain. You can't say this one is grieving, this one's hurting more than the other one. Pain is pain, the other one maybe lost her dog, maybe her pain is just as real as mine! But you can't weigh it, you can't go out and tell me, 'Well, you know, it would have been a lot worse if they would have lived.'" Like I said, "No one knows what it's like. Yes, maybe, if they would have lived for a year or two, it would have been really hard, I guess. I would have had memories, I could have said, 'Here are my pictures, I held her, this is with her clothes.'" I said, "You know, I never even got to touch them." So I said, "You know, the person to say that.. absolutely does not know."

#### 9.4 Self-Changes and Transformations

*My life is broken in two in my mind  
Before Jacob  
And after Jacob  
I don't recognize the person I was before  
Most days, I like the person I've become.  
Because of you...  
I hope I'm a better parent and a better person  
My faith in God has been strengthened  
(but sometimes I'm still angry at Him)  
I'm more compassionate  
(but sometimes more impatient)  
I have a greater sense of what really matters in life  
(but I still get caught up in things that don't matter)  
And since you can't be here with me  
I'll do my best to create something positive  
Out of the heartache and agony of grief*

*~Myrna, 2004*

Consistent with previous research (e.g., Davis, 2001; Braun & Berg, 1994; Calhoun & Tedeschi, 2001), the parents I interviewed spoke of self-changes in three realms: changes in perspective, philosophy, priorities, values, and beliefs; changes in relating to others (interpersonal realm); and changes in personal characteristics. Although recent bereavement literature has focused on changes in terms of the positive transformative power of grief, I have chosen, instead, to highlight both the positive and negative self-changes, as a reflection of the reality that these parents voiced.

In the discussion that follows, the parents' words are presented verbatim, but I have created a group conversation between them that obviously did not occur in reality. My decision



to do this arose when I examined the excerpts from each of their stories pertaining to self-changes, and I was struck by the commonalities in the types of changes identified by such a diverse group of individuals with unique loss circumstances. In Davis's (2001) discussion of benefit finding, he noted that the specifics of the death serve as a catalyst for the emergence of beneficial self-change, but have little to do with benefit finding otherwise. Perceived benefits seem to have more to do with the experience of adversity and grief than with the particular circumstances of the loss. The very similar changes that came about for the parents and for me appear to have emerged from our *struggle with our grief* (Tedeschi & Calhoun, 2004) and the reactions of our social networks, rather than being unique or specific to the details of our losses. The fact that I was able to bring these parents into "conversation" with one another with very little altering of their words is a reflection of this phenomenon.

#### 9.4.1 Changed Life Philosophy, Values, and Beliefs

Myrna: So, do you feel like you've changed at all?

Owen: You can't possibly go through this without being changed. It puts a lot of other things into perspective, so.. you worry a lot less about some other things.

Luke: Yeah, the little things don't matter. And maybe they should. I don't know. But things that used to matter to us don't matter at all any more. And.. some of the things when you think, you get upset about, and wondering why in the hell you even.. (*laughs*) get upset about these little things.

Sonya: It does give you a totally different outlook on life. Totally different outlook on life. I mean.. (*sigh*).. I used to get upset about different things, like let's use work, for example, and I just don't anymore, it's just insignificant, it doesn't matter. So your view on what's important, what's not important.. I mean, you can take this gorgeous house and give me a shack if you could give me Alanna back, I mean, I'd even live on the street if I had to... So you just.. what's important, what's not important has just sort of really, really changed, and it's allowed you to look at the world with a different set of eyes.

Katrina: For me, I feel like I don't have to rush as much as I used to in life, I don't know. 'Cause I mean.. just take things slow. Instead of always so fast, because life just goes by so quick. And anything can happen. Not to get so upset over little things. But I still do, little things.. (*laughs*)

Myrna: (*laughs softly*) mmhm, I still get caught up in the little things too. What about you, Mona, have you changed, do you think? Even in.. you know, your thoughts, your beliefs.. whatever?

Mona: Hm.. I guess I kind of took a lot of things for granted before, and now, like Katrina said, I've slowed down a little more, and done.. I haven't done anything.. a *whole* bunch different, but.. when I do something, I think of the impact that it's going to make.

Stacie: I've noticed it has *definitely* changed my attitude on the children I have. Like, not that I didn't love them 100% before..

Penny: For me too, I think that's what I've done, I've learned to appreciate what I have, by.. not downplaying what I went through, but by seeing some other people who.. either can't have other children, or.. like a lady that works for me, she had 4 kids, 2 sons got killed when they were older. You know. For me it's probably made me more thankful for what I have. Which maybe is strange, but.. it is, I don't dwell, I can't dwell on what I could have had. I feel bad, and I always will feel bad, but on the other hand, I have to be thankful for what I have.

Sonya: (*Nodding and rubbing her pregnant belly*) Yeah, I know I'll appreciate our next baby even more because of what we've gone through. I think the other thing is you just appreciate the miracle of birth, when you find out everything that could go wrong, you just realize, this is a miracle! And it.. you know, for me, you look at parents who have children and they don't appreciate them. And it's just like, "You don't understand how precious that little person is, and what a miracle that was, that he came into the world, or she came into the world."

Stacie: I work at a doctor's office, and there are times when I get angry, because you get some woman coming in, 'cause her social worker's bringing her in, and she's 9 months pregnant and drunk, and they're sending her to some home to have the baby, so she's at least *sober* when it's *born*. And you're looking, going--, you know, and she's going to have a perfectly fine, alive child. You know, or.. people's children being taken away by social services. And it's like, okay, well where's the *justice* there?

Owen: It's funny, I mean, you listen to people complain about their kids all the time and stuff. You know, (*sigh*) or goofy things the kids did, and stuff. And you think, "Oh, man, you have no idea." But.. all I know is, at the end of it, you have a real sense of powerlessness really, about the whole thing. Ah.. and from the male perspective that's a very difficult thing. Ah.. that there's nothing I could do to.. prevent this or to change it or anything.

Sonya: Yeah, powerlessness, I guess that's maybe the biggest thing for me, now that you've used those words, is I'm a control freak. Or was. And I've lost that, because now I realize I just have no control over the most important things in life. I used to plan my day to the minute and all that sort of stuff.

Owen: I'm telling you, that sense of control is such an illusion. I mean a cell, a little tiny cell, when a baby is conceived, maybe a million cells in total or something, forming and doing their thing. Little stem cells and stuff. And for our daughter, one just made a little detour somewhere so that she had a severe heart defect. And you can't.. nothing you can do to control that.

Myrna: Yeah, no control at all. That was a shock at first, and a real source of the guilt and self-blame for me – I figured there must have been something I could have done to prevent it. But now, I've come to realize that maybe I have to accept that I can't control the direction my life takes, but only what choices I make in the face of reality.

Andrew: I believe that too, I think that okay, if there's a purpose behind this, I have to find out what that purpose is. And if I don't find out then I've got to figure out, okay, what am I supposed to do with what I've been taught? How can I turn around and use it to benefit instead of being detrimental? 'Cause everything can be turned around and used for benefit.

Mona: I guess I've.. thought more about that too, that everything happens for a reason. I still don't know what the reason is for this. But I definitely believe that there's a reason for everything now.

#### 9.4.2 Changes in the Interpersonal Realm

Myrna: Judi, you said in your e-mail that it's.. formed who you are. Can you talk more about that?

Judi: Oh sure it has. Ah.. I think now I can't.. commit complete love towards others. Maybe that's why my husband and I have had some marriage problems. Because there's still part of me that's.. not going to get caught again. I'm not going to allow myself to get hurt emotionally.. to love that much again.. as devastated as I was.. it just cost too much.

Myrna: mmhmm.. I noticed that all the significant people in your life were in the background of your story. Maybe that's a reflection of how you distance yourself to avoid getting hurt again. Does anyone else think they've had negative changes in how they relate to people?

Luke: I'd like to think I haven't become harder. I guess the worst thing is sometimes I feel like I'm not going to bend over for people backwards anymore. People that I thought should have said sorry or something to me, and said nothing.. I just put them in the back of my mind. And I know that's terrible. But maybe when they go through something, maybe I'll be the same way they were. I had a real good friend of the family, they've got a son that's 21 years old. And he was just in the hospital. He had a breakdown or whatever. I made a point of seeing him once. But after that, it's if I only had time. And.. sad as it was, the reason I wasn't going to go out of my way to see him more than once was because I didn't even get a sorry from them when our little girl died. And I know that's not right, and I do care about the guy, he's only 21 years old. But I.. I guess that's the only way I've changed. It's not like I'm trying to get even with people, but it's just all up there, how people acted when.. our little girl died. It's all up there in how they treated me and Katrina (*soft laugh*).... So I don't know if that's right or wrong, but maybe.. there is no right or wrong.

Myrna: And that might change over time too, you never know, it's still so early, you can't judge anything based on how you're feeling now.

Luke: Yeah, that's for sure. So I'd like to think I'm not going to be hard on.. other people because they reacted towards our baby dying, but~

Myrna: It's hard to get past that hurt though, if you ever do, you know. Dan and Stacie, you mentioned some changes in friendships too, didn't you? Some friends who had a baby the same day you did? Or maybe that was more because of a change in them than in you?

Stacie: Yeah, we were with them quite a bit, right after the babies were born. And afterwards, we hadn't seen them for a long time, and out of the blue, he phoned and said we should come over. And then the guys went out, and she and I stayed with the baby. And she's like, "Are you comfortable being here?" And I said, "Yeah," I said, "you know 'cause he's a cute kid." You know (*laugh*). I said, "Yeah, I'm very comfortable" and.. I think just, like that's.. pretty much from there is where it just kind of went downhill. And the questions she'd ask when I was there, it was almost like she was always unsure of herself, like, "Am I boasting, am I.. throwing this in your face, and I don't want to." So she, she chose, I think, to avoid, instead of~

Myrna: mm, kind of avoided you. Sharon, you said you noticed changes in how you are in your relationships, right?

Sharon: Yeah, I mean, in my life, I've gone way more into a kind of life that involves.. *deep* spirituality. And not from a religious standpoint, but where I do think a lot about death, and, you know, I'm just very philosophical in my life, and things that I do in my life have to be things that matter, and have deep significance and deep importance. And, basically I really don't have time for people who don't want to deal with things on a deeper level. I mean I have lots of acquaintances, but if they don't have anything to talk about other than.. you know, the latest fads, (*laugh*) or whatever's going on in the material world, I mean to a *certain* extent, you do get together and, you know, "What are you doing in your house, and what are you decorating, and what are you sewing right now?" and.. that kind of stuff. But there's a certain amount of that, and then it's got to go somewhere a little bit deeper.

Andrew: I'm different in my relationships too. I think now I find new ways to deal with stuff, I don't deal with things the old fashioned way I used to, like, drowning it, ignoring, bottling it up. Particularly with the relationship I'm in now, instead of letting things sit and stew and whatnot, we talk it out, and as soon as something happens, I guess we talk about it right away. We ask each other how we're feeling, that's something I would never have done, I would have taken it, say, "Oh well, water off a duck's back," and just bottle it up and let it sit and eat away. That's something I would never do now, even the *thought* seems kind of horrid to do that.

#### 9.4.3 Changed Personal Characteristics

Myrna: So would you definitely say you've been changed, transformed?

Andrew: Yeah. mmhm. Definitely, because.. the person I was and the person I am are two different people. I still have some of the same old.. instincts or thoughts that I used to have, but I'm not the same person anymore. There was a spark of me, the way I am now, in my past when I found out I was going to be a father, that's when the spark was first lit, that I didn't want to be the way I was for the rest of my life and I was going to be there for this family I was making. And, in spite of.. having that family taken from me, the fact that that spark is going to continue with my new family, it's going to help when I, when I do become a father again, *if* I become a father again. And.. hopefully I'm.. my little girl's going to live on in terms of the work I'm doing with youth, and live on and her spirit will continue to help others as she helped me, because, there've been times where I'll be sitting there and I'll just be, just down and depressed, and got the weight of the world on me, and I'll feel that little presence. And then I'll just perk up right away.

Dan: I'm trying to be a.. a better person because of my daughter, too. Um, I forgot.. and lost my way.. before. But when I start thinking that I'm losing my way, I think of her. And she kind of puts me back on the straight and narrow. She's a Godsend, a lifeline.. a guardian angel. She's the power behind the throne, kind of thing, you know. She's sitting there, well, that's what I called her is, "my little princess," daddy's little princess.... I've noticed other changes too. Sometimes I'll be sitting, and I'll be watching the *corniest* T.V. program, and something will happen, and it's all I can do to keep myself from crying. You know, and it seems like I've become more emotional since, and ah..

Sonya: Yeah, I can cry at a T.V. commercial now, just because you can feel for what that person-- , you know that, that.. gut wrenching, horrible feeling of pain. And so you have a little bit more empathy for somebody, so you can talk to them a little better, and help deal with things a little better and stuff like that. It's made me a better.. listener I guess.. in terms

understanding people. I always thought I was, but.. until you go through something like this, I just, I don't think you can really truly.. appreciate~

Owen: The thing that really struck me afterwards was, you notice all the tragic stuff that you never noticed before. Especially when it involves children and stuff, and the random events that happen. Ah.. like it was sometime after this happened.. it was a very tragic accident in Toronto or somewhere. And ah, it was a strange story, there was ah.. a mom was out on the front step, and the child was playing on the front lawn of the house. Some guy came along, a drunk driver in a ½ ton truck. And went over the sidewalk and through the front yard. And this little boy, 8 years old or something like that, and ran over him right smack in front of his mother in the front yard. And you hear that, and you go~ But before I would have had no.. understanding for what that was like. And, and you think.. oh-h, boy.. that's.. you know, some mother had to watch that..

Deena: I think I'm more sensitive too, especially about kids. Like I think about.. little kids more. I'm more sensitive to people's feelings maybe. 'Cause I feel.. like I feel I was.. kind of neglected, you know?

Myrna: mmm, yeah, not a lot of support at all, it makes sense that you'd be more conscious of other people's feelings.. I think I'm more sensitive too, or touched more deeply by others' pain than I used to be. I'm more aware of how important it is to reach out to people who've had a loss... I feel more comfortable sending cards or expressing my sympathy at funerals, whereas before I never knew what to do. And I think I'm more sensitive to all kinds of pain, not just other people's grief.

Stacie: Me, I'm more.. I don't know, it's hard to admit, but before I was a more happy-go-lucky person. Took day-by-day, you know, who cares, whatever, whatever comes. And *now* I'm more cynical, definitely. Definitely. More.. I don't find myself as giddy as I used to be all the time. I mean, I don't think I'll ever be that way again. And.. crying. Like, before, you know, women's stuff, I'd be {mimics sobs} And *now*, I almost have thing of.. *nothing's* worth~ Like, *my* tears, I shed for my daughter. If *you're* not on the level of my daughter.. you ain't worth my tears. You know, 'cause to me it almost feels like, well, if I cry over just *any* little thing.. it kind of deadens.. what those tears meant for her. So it's got to be a *pretty big* thing to bring me to tears. So that part of me changed, I'm not as sensitive anymore. {laugh} But it's actually.. it's made me definitely a *stronger* person.

Penny: Yeah, even though I.. still some days I.. you still go, "Why did it happen?" But I realize, probably.. you do become stronger. You have this inside strength that.. I, I think.. really prepared me for a lot. Now, at the time, I think, you didn't realize that you were gaining strength while you were going through all this. But it's.. you know, yeah, I think it does change you.

Rachel: Yeah, everything makes you stronger.. well, unless you let it.. break you down. You know, some people do that, but.. But if you can deal with it, and.. come through it, it usually makes you a.. a stronger, better person in some way. I know, as a special ed. teacher now, I could never have done the job I'm doing now when I first started teaching, I wouldn't have had the patience. But now.. I can sit with those kids, and it doesn't bother me that they don't get it the first time or the 10<sup>th</sup> time or the 15<sup>th</sup> time, you know. But I've sort of figured out over the years that you don't know.. how you would handle it. Like if somebody had told me that I would go into the hospital someday and have a baby and walk out with a dozen roses



instead of my baby.. I would have thought I'd just die. You know, like how could you.. ever.. stand it? You know. But when the time comes, you have to deal with it. You do.

Katrina: I thought I'd be worse when it happened, too. Like I was sad, but I don't know, I just... Like I was upset, but I thought I'd be more upset than I was. It was very hard, it has been bad, but I thought I'd be worse than I was, like I thought I'd just be falling right apart. I've been stronger than I expected. Maybe because I went through infertility, and went through all that, and.. and, I don't know, I guess things happen, and~ 'Cause sometimes I'd be really mad, 'cause I was trying to have a baby I was mad at other people that could have babies. But now the people across the street had a baby, but I'm not as angry as I thought I would be. I wasn't as jealous and angry as I thought I'd be. Maybe I got all that frustration out when I was trying to have kids... I can also say things to people that I never would have before. Like, "Jeez, it pissed me off when you never said anything when my daughter died.. never said sorry to me." Like now, I could say something to people.

Myrna: Yeah, my view of how strong I am has changed too. I feel more sure of myself, more confident, and I care less about what others think.. It's like, I've experienced the depths of devastation and there's not much that could be worse than that – and I know I can survive. So failing at something, being negatively evaluated – it just doesn't matter to me like it used to.

Dan: I spent my life trying to look tough because I was teased as a kid. And I don't care about looking tough anymore, you know. I don't have to be tough. I was there for her. That's all that matters. It didn't matter how long my hair was, or how many tattoos I have, or.. how much beer I can drink..

Myrna: yeah... it's a hell of a lot stronger to be able show your grief for her.... A lot of you have talked now about changing in really quite positive ways. How about for you, Judi, you mentioned that you've changed, but it doesn't sound like you feel that there's anything positive at all?

Judi: No, oh no, no. No, this was... a *hell* of a life in the making... It was probably the wor--, as far as I'm concerned, this is the *worst.. thing..* that could happen to *anybody*. I can't imagine *anything* happening.. like this. I mean, I've lost a *parent*. I've lost a *fiancé*. I've lost *friends*. But my own flesh and blood.. which *didn't get a chance*. I don't think it would have been so bad if he had had some small life and he was ill, and they were trying to take care of it and all~ But he didn't have a chance in hell! No, it was the worst, worst thing in my life. *Worst* thing in my life...

Sharon: You know, at different times over the years I would have agreed that I experienced only negative changes, too. Several years after my daughter died, I was to the point of not caring anymore, making a quasi-suicide attempt. At *that* time, I would say I was *very* depressed then. *Very* depressed. It's interesting when I look at family pictures, you know, kind of back then, and I'm always smiling and happy, and I'm thinking, *oh boy..* what was.. you know, there was so much below that, and behind that smile. I was a *very* disempowered woman. *Very* disempowered woman. But when I finally took my grief and memories off the "shelf" I had put them on, I.. I'm going to try really hard to avoid that word 'heal', because I don't like it. I don't think you ever *heal* from this. But it does, there is, there's *soothing*, there's.. you know, a better sense about.. what happened in your life, a better perspective on it.

Andrew: When this first happened to me, it just seemed like.. this is.. the end of the world, it's always going to be like this I'm always going to feel this bad, and, it's going to hurt for the rest of my life. And, if I had had somebody tell me "No! It's not going to, the only way it's going to hurt for the rest of your life is if you *let* it, if it just sits there, then it's going to hurt." And, if I had known that I probably would have handled things a lot differently than ah.. than the way I did. But like I said, if I hadn't done those things, I wouldn't be around today, I wouldn't have had the opportunity to do the work I'm doing with the at-risk youth. And I'm hoping that I'll be able to help somebody, help with this research, and the fact that, that from this pain, from the pain of having lost a child, and the pain of having to go through all that I've gone through, the fact that there will be a positive aspect coming out of it in the long run, that's, that's a very healing thing, and hopefully through this, other people will be able to be healed. That's one thing I'm really hoping is that nobody will have to go through the kind of pain and sorrow and anger that I went through.

#### 9.4.4 A Word of Caution

Myrna: Is there anything in particular that helped you to.. survive, helped you to make sense of stuff, or did you ever make sense of it?

Penny: I don't know. Do you ever make sense of it? Like, you don't understand--, there's one thing that someone told me. People used to say, "Out of every bad situation, there's something good comes out of it." And the next person said, "No, that's not right. You learn from it. But that that's not right," she says, "there are situations that are really sad.. and bad situations that there really was no sense to it, and there's nothing good that came out of it." Like really, when you think of it, losing three babies, I can't say anything good came out of it per se, 'cause I don't have my three babies. Maybe it's helped me to change my way of thinking, and.. made me a better person. But I can't.. what good came out of it? Like maybe it made me.. probably enjoy my other ones, but I would have enjoyed them anyway.

Myrna: Exactly. For me, maybe I appreciate life more, and recognize my blessings more. And take less for granted. But I still don't believe it was necessary for my baby to die in order for me to learn these things. I'll never really understand why this happened to us. Not that I think it should happen to other people, either...Why does it have to happen at all?

Sharon: mmhm, yeah.. I corresponded with a women named Donnali Fifield, who wrote some internet articles and a book about the deaths of her twin sons<sup>30</sup>. She said some interesting things about this idea of positive changes coming out of grief that makes a lot of sense to me.

Myrna: Yeah, you gave me that article<sup>31</sup>, I have it here.. (*reaches for some papers and flips to a marked page.*) She says:

*During the first years, I blamed myself for not recovering. The real culprit: the now-conventional interpretation of grief as a vehicle for personal growth and healthful,*

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<sup>30</sup> Fifield, D. (2000). William & Wendel: A family remembered. San Francisco, CA: Binary Books, Times Two Publishing Company. Retrieved March 3, 2002 from: <http://www.timetwopublishing.com/binarybooks.htm>

<sup>31</sup> Fifield, D. (2001). Aggrieved: The bereaved have to cope with their loss – and the pressure to heal. In *Kota Press Loss Archive, 2001, Volume 2* (Issue 8; December 2001). Retrieved September 3, 2005, from <http://www.kotapress.com/FrameLoss.htm>.



*completed healing. The idea of closure was only a theory, but it had infiltrated my thinking, and everyone else's, becoming accepted as true... Why should loss always be an occasion for emotional growth? Why must it be talked about as a catalyst for personal improvement? Bitterness is just as likely, and just as legitimate, an outcome. I would guess that most people, if they were allowed to speak freely, feel a mixture of emotions years after a trauma – more compassion, a greater understanding of mortality, envy of those who have not had the same loss, anger underneath the surface, rising up quickly whenever circumstances again take away their sense of control. The darker emotions, however, have no place in the grief experts' narrow definition of resolution. Their goal is emotional health. A humbler approach, conceding the complexity of human responses, is far more helpful.*

#### 9.4.5 Conclusion

The preceding “group discussion” illustrates a number of things about self-changes and transformations following a perinatal loss. First, the remarkable similarity in comments made by such a diverse group of parents speaks to the seemingly “universal” (within the context of western society) nature of the occurrence of changes of self following this form of loss. As with survivors of some other forms of loss and traumatic adverse events, these parents demonstrated how they changed in very similar ways because of their struggle with grief and the reactions of the social/cultural world in which they were embedded. Importantly, self-defined “negative” self-changes were not uncommon, including increased self-protective behaviours in response to the pain of the lost relationship or the lack of social support following their losses, increased cynicism, and impatience with others (for reasons pertaining to their own changed perspectives, such as perceived superficiality and misplaced priorities of others). The importance of this observation lies in the tendency for bereavement researchers studying the transformative power of grief to ignore the negative self-changes in favour of studying the positive. While positive changes are clearly common and it is important that they be better understood by researchers and clinicians, a more complete picture of the self-change phenomenon following grief is necessary given that both positive and negative self-changes can take place in the same person. As Donnali Fifield conveyed in the above quote, the most helpful approach would be to come to an understanding of the full complexity of self-changes that follow a loss, rather than a one-sided view of this phenomenon.

#### 9.5 The Relationship between Meaning-Making and Long-term Grief

*Scene: It is late in the evening in early September 2005. LeRoss is sitting on the bed in a master bedroom, reading a computer programming book. Myrna enters the room with a handful of papers in her left hand, a pen in her right. She flops down onto the bed with a sigh.*

*LeRoss: (glancing up from the book) How's it going?*

*Myrna: (Drops the pen and papers and rubs her eyes.) Crappy. This is never going to end.*

LeRoss: It'll come. Where are you at now?

Myrna: I'm on the last section of the chapter, and then I'm onto the final discussion. How can it be September already? (*Sounds despairing*) This is ridiculous! I thought I'd be finished months ago, and here I am, dragging all of us through month after month of being in limbo.

LeRoss: We're fine. Just keep at it, you're almost there. (*He puts a bookmark in the book and sets it on the bed*). So what's the last section about, again?

Myrna: (*sighs*) Well, I'm trying to show how meanings ultimately affect grief, especially over time, as in long-term grief. It's what we were talking about when I first started this chapter, that our meanings or perceptions of our loss experiences can determine what our long-term grief is like – and that some people need to revise their meanings before their grief will evolve to a more peaceful state. (*LeRoss nods.*) But.. I'm so sick of thinking about this. (*She sighs again and covers her head with a pillow.*)

LeRoss: (*LeRoss watches, and then speaks gently after a moment.*) Doesn't it usually help to think of how these issues apply to you, first?

Myrna: (*sighs*) Yeah.. I guess.. (*Sits up and runs her hands through her hair, thinking.*) For me, finding positive meaning after Jacob's death was – sometimes still is – a significant struggle. At one point, I believed finding positive meaning in Jacob's death was the key step in my grief that allowed me to keep functioning in a relatively healthy way. Now, I would say it differently – that obviously there was nothing positive in his death per se, but that through my search for meaning and my struggle to learn to live again after he died, I identified some positive meanings and changes in myself<sup>32</sup>, which in turn soothed me in my grief. Like I came to appreciate what really matters in life, and I became more compassionate in some respects – even if I'm less patient with people in other ways. (*Said with a sheepish smile.*)

LeRoss: (*snickers*) Yeah, I've noticed the impatience.

Myrna: (*makes a face at LeRoss*) Ya ya. Anyway, here I am talking about positive changes rather than how meanings affected my grief.. I guess it's hard to distinguish the two. The meanings I came to maybe helped me to recognize the positive changes, or maybe voicing my recognition of positive changes *is* the meaning I've come to.

LeRoss: Can you say that again? I'm not sure I'm following.

Myrna: Well.. it was life-shattering to lose our baby, but maybe I was able to learn to live again *because* I was able to find, and in some cases create, positive meaning – the meanings *being* the positive changes I just talked about, as well as the positive things I've tried to *do* as

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<sup>32</sup> Tedeschi & Calhoun (2004) describe post-traumatic growth in this way.

a result of Jacob's death, like trying to help others as well as myself through this project. In some ways, my grief was *eased* by being able to identify some positive meanings, changes, or actions that I could take. How about for you? Do you see any relationship between your meanings or changes you went through and your grief? Like wouldn't you say that joining Big Brothers and taking on the disabled water-skiing clinics are positive things you've done *because of* Jacob? And how does it relate to your grief?

LeRoss: hm.. (*long pause as he thinks, tapping his fingers rhythmically on his knee.*) I wasn't able to relate to Jacob through the pregnancy like you did, so getting involved in those things are my way of striving to do things that I might have been able to do with him... I feel like I'm achieving things and helping other people achieve things.. kind of like you do with your kids. It kind of fills in or patches the gap, what I missed out on with him. Kind of redirects your energy, your grief, in a positive direction.

Myrna: mmhm, mmhm. (*Sits up straighter, with passion and determination evident in her voice again.*) For me, it's like these positive meanings and changes are Jacob's legacy, and so even though his death will always seem senseless, at least he'll live on through his legacy. And that gives me some comfort, some solace, some peace, despite ongoing waves of grief that will keep returning as long as I live. And, especially before Caleb was born, it gave me a renewed purpose in life even though I still ached every day.

LeRoss: mmhm. So what about the parents you interviewed?



#### 9.5.1 Patterns of Long-term Grief

Before discussing the relationship between parents' meanings and their long-term grief, three definitions are in order to distinguish between the patterns of long-term grief to which I refer. As I considered this issue in each of the parents' stories, it appeared that their long-term grief fell along a continuum, with the endpoints being what I have called *buried grief* or *unchanging grief* and *peaceful/evolving grief*. In her study of mothers who lost an only child, Talbot (2002) proposed such a "continuum of bereavement". Her qualitative description of mothers who represented the endpoints of this continuum is in good agreement with what some of my participants described in their stories.

Those mothers who Talbot classified as being in the *perpetual bereavement* group continued to experience intense grief years afterwards but did not discuss their grief with others or actively seek out support groups, and they were reluctant to do so. Some believed they had experienced negative self-changes. They often lacked an adequate support system and coping skills, and they suffered psychological instability and stress-related physical symptoms. Some

were ambivalent about living, were angry with God and/or church and were unable to reconcile their child's death with a beneficial belief system. They focused on reviewing aspects of the loss and the effect of perpetual grief on their lives. In contrast, the group of mothers at the "survival" end of the bereavement continuum continued to feel grief but it no longer dominated their lives. They discussed their grief with others, often at support groups, and they experienced family and friends as being helpful. They viewed their spiritual beliefs as helpful to them, and they had dealt with any spiritual crises they had experienced, resulting in reconstructed spiritual meanings. Identifying positive meanings and self-changes was common with this group. Some indicated they had made a conscious decision to survive and reinvest in life. They had struggled greatly with acute trauma and grief, but had managed to integrate what they had learned from grief into a new identity and worldview.

With Talbot's continuum of bereavement in mind, I conceptualized the long-term grief of the parents I interviewed along a similar continuum. In no instance did a parent report that they no longer grieved, even (or especially) those whose losses occurred decades ago. Many seemed to be closest to the "peaceful" end of the continuum; several others were closer to the "buried" or "unchanging" end of the continuum at the time of the interview or for several years after their baby died, before they reached a more peaceful (but still evolving) state in their grief. My modified terms for grief patterns at either endpoint of the continuum reflect my perception of an important difference between long-term grief over a baby dying in the perinatal period and grief over an older child.

*(1) Buried Grief:*

*...it isn't the **fact** of the baby, the **fact** that he lived and died, that's **not** what I buried. It was the **grief** I buried. First I wasn't allowed to grieve, and then I didn't allow myself. And grief unexpressed is... it's almost like a disease, a cancer in a way. Because it doesn't go away, it eats away at you. And it's destructive. (Irene)*

Talbot's and others' studies of parents bereaved of an older child speak of perpetual, chronic, or debilitating grief, but never buried grief<sup>33</sup>. For the mothers that I interviewed whose losses occurred decades ago, buried grief was highly likely because of the disenfranchised nature of the loss. For these mothers, buried grief meant that they ignored, inhibited, or did not acknowledge their grief for many years. This appeared to stem directly from the disenfranchised meanings imposed on them by their social networks, which they sometimes came to believe

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<sup>33</sup> Bereavement literature on pathological grief uses the terms "delayed" or "absent" grief (e.g., Middleton, Raphael, Martinek, & Misso, 1993) that are similar in some respects to what I have called "buried" grief. My view, however, is that the assumption of pathology underlying these patterns of grief makes them inappropriate terms to describe what was experienced by these mothers.

themselves (as Irene put it, “First I wasn’t allowed to grieve, and then I didn’t allow myself”). Sharon, for instance, spoke of her “shelved” grief and memories, and not recognizing that her loss was “a big thing”; and Irene described her grief as being “buried” or stored in boxes in her mind.

### *(2) Unchanging Grief*

*The grief is always there. There’s no getting away. You can cry yourself silly, and the grief will never stop. There’s **nothing** you can do about the grief. It’s ripped my heart out and choked me and thrown it away. That’s what it’s done to me. I’m empty inside because of him.. (Judi)*

Like Talbot’s description of perpetual grief, some of the mothers whose losses occurred decades ago described their grief in a way that suggested it had changed little over the years. That is, they remained in a meaning crisis, unable to incorporate the loss of their babies into a renewed perspective and purpose in life, suffering from psychological distress, and feeling no peace with their losses. This is not to say that they grieved openly. Rather, they acknowledged the magnitude of their losses to themselves but they did not seek support or find an outlet through which they could openly mourn their losses. Judi, Deena and Penny, described their grief in ways suggestive of unchanging grief for many years after their babies died. They appeared to have acknowledged the depth of their sorrow within their own minds, but they stifled their grief.

### *(3) Peaceful and Evolving Grief*

*...it sounds so cliché to say that time heals, but it really does. Not that you just **let** it heal, you have to deal with it and work on it yourself, but.. over the years it does.. get easier... I guess every year on his birthday I.. go through the whole day, you know, right from.. when I had the first pain until I delivered him. For several years I did that. Just going over it, and.. probably crying. But.. it wasn’t that I cried.. a lot or for a very long time, but.. I mean, that’s how grief is, I learned that after losing my husband, that.. one book I read said that grief is like the waves of the ocean. And at first they’re huge and they.. crash you down. {emotion in voice} And then they just get smaller and smaller, they don’t go away, but they’re.. they’re smaller. {crying softly} .....But I think we just thought of it as..... that’s what it was meant to be, so... [it’s a comforting thought, but] you still have to grieve... (Rachel)*

Like Talbot’s description of the “survival” end of her bereavement continuum, *peaceful/evolving grief* describes the long-term grief of some of the parents in this study, most of whom had their losses in the 1990s or later. I use the terms “peaceful” and “evolving” because they describe what I see as the essential characteristics of this pattern of long-term grief: “peaceful,” because the parents were at-peace with their losses, having incorporated any meaning-crises that were triggered by the losses into their reconstructed identities and life

philosophies; and “evolving” to reflect the ongoing, lifelong, and ever-changing nature of the grief that these parents described having for their babies who died in the perinatal period.

#### 9.5.2 *The Impact of Meanings on Long-term Grief*

Nadeau (1998) commented on the importance of future research addressing a question raised by her study on family meaning-making – specifically, “how attaching particular meanings to the death affects the course of bereavement” (p. 166). She noted that those who could find no meaning in the death, or a meaning that did not give hope, found their grief more difficult to bear. Others who felt they had grown in positive ways because of their experience with grief had a more peaceful tone to their grief (i.e., such meanings sustained them in their grief). Like Nadeau’s and others’ findings, the parents who told their stories for this project demonstrated that the meanings that were found or made after their babies’ deaths affected how well they came to terms with their losses. Similar to Bernstein’s (1998) and Talbot’s (2002) studies of parents bereaved of an older child, these parents adapted more readily and in a healthier manner if they found new and positive meaning in life. Consistent with Rosenblatt’s (2000) study of parental bereavement, some of the parents also noted that reinvesting in life and finding hope was a conscious choice, not an automatic outcome to be reached with time alone.

The essential aspect of meaning-making for the grief process of the parents I interviewed was that whatever *meanings* were made appeared to *determine* where they fell on the grief continuum 1, 5, 15, or 30 years later. For example, if the meaning they *arrived and stayed at* was that they were responsible for their babies’ deaths, or that they were responsible for some aspect of their babies’ suffering, then unchanging or buried grief and psychological struggle was more likely. Or, as with most of the mothers whose losses occurred before the 1980s, if they were told or believed their losses were insignificant, they suppressed or ignored their need to grieve, and the meaninglessness and grief remained in the back of their minds and seeped out gradually and eventually, often having very detrimental effects on their psychological and emotional well-being. This is a rather simplified conceptualization, because the parents’ efforts to make sense of their experiences were obviously far more complex than these examples. But regardless of the complexity, and sometimes inconsistency, of the meanings they ascribed to their experiences, their meaning-making attempts had a clear impact on their long-term grief.

The meaning-making strategies discussed previously (spiritual meaning-making and hierarchy of grief comparisons) can be viewed as internal processes or choices that take place within the necessarily complex context of individuals embedded within their social/cultural worlds. “Strategy” refers to something that can be changed or reconstructed, such as a deeper contemplation of spiritual beliefs or re-conceptualizations of one’s worldview (e.g., accepting that



having control over some aspects of life is impossible). In contrast, the meaning-making “influences” that were discussed come from external sources that cannot necessarily be changed, such as societal views and responses that serve to disenfranchise a perinatal loss. Although such *responses* were not under the parents’ control, some parents came to a point where they were able to resist the *influence* of these external forces on the meanings they attached to their experiences. Other parents, however, had remained in a state of only being *influenced* by these negative meaning-making influences rather than *resisting against* the influences and adopting strategies that would help them reconstruct their meanings. They appeared to continue to accept their original assumptions and beliefs as a way of making sense of their experiences, rather than actively searching for new meanings and purpose. Parents who were at the peaceful end of the grief continuum were those who found a way to *actively* choose to live again, as opposed to those who appeared to only survive, going through the motions of life but not reengaging in life with new hope and purpose.

For many parents, finding meaning that moved them toward peaceful grief appeared to be more difficult if they had complicating circumstances, such as: having multiple losses; being a single mother; being childless parents or having older children but being unable to have more because of their age or fertility problems; losing a baby from a set of twins; having a stillborn baby; watching their babies suffer before death; having especially traumatic experiences and memories from the period surrounding the death; having a baby with multiple birth defects; having an unsupportive or abusive spouse or serious marital problems in general; lacking support and being told by others (and sometimes accepting the meaning themselves) that their loss was insignificant; and viewing the death as preventable and believing it occurred because of medical incompetence.

Meaning-making seemed to be less of a struggle, good psychological health was maintained, and grief evolved to a peaceful state more quickly if: parents recognized the significance of their losses and did not inhibit their need to grieve and process traumatic memories; they were shown compassion and had supportive listeners amongst at least some of the people around them; they held previously existing beliefs or found soothing meanings to contend with the meaninglessness of a baby’s death, such as believing that there was spiritually-based meaning and purpose for their babies’ deaths; they were given the opportunity to mourn through rituals that they planned and conducted themselves (this meaning-making strategy served as a way of establishing meaning – helping them to firmly establish for themselves and demonstrate to others that their losses were significant); and if they found a way to release themselves from meanings involving self-blame.



For some, the ultimate psychological impact of meaninglessness and buried or unchanging grief was evident in the form of depression, self-hate, substance abuse, and suicide attempts even decades after their losses. While mired in buried or unchanging grief, they saw no positive changes, or did not emphasize such changes (e.g., Judi; Irene only acknowledged the positives after many years of buried grief and meaninglessness). Caught in a circular, self-perpetuating process, buried or unchanging grief prevented these parents from engaging in the “story telling” or narrative reconstruction of meanings and processing of memories that was necessary for them to escape the grasp of their traumatic experiences and disempowering meanings. For those who were entrenched in meaninglessness and buried or unchanging grief before fully acknowledging or experiencing their grief, a revision of their meanings about life, death, and themselves seemed necessary before they found peace with their grief (e.g., see the discussion about Irene at the beginning of this chapter). Such revisions were often only possible once the parents found a caring context of a compassionate listener (e.g., Sharon’s friend Karen), or a counselling-type setting which helped them to (re)experience their grief and reconstruct their meanings (e.g., Irene’s rehabilitation experience; Penny’s counselling workshop experience; Andrew’s aboriginal culture healing circles).

Those parents who more readily made sense of their losses within their existing life philosophies or actively constructed alternative worldviews appeared to be closer to the peaceful end of the grief continuum much sooner after their losses. This is not to say that they did not have ongoing struggles with issues of meaning, but that they were able to grieve and their grief evolved into a more peaceful state, rather than being immersed in years of meaninglessness, self-destruction, and disempowerment. They were also more likely to identify or create positive changes *because of* their experience of grief. That is, identifying positive self-changes did not seem to be the essential process that aided parents in moving toward peaceful grief. Instead, finding peace with the meanings of their loss and grief appeared to *establish the necessary conditions for* identifying or creating benefits.

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*Thoughts are flying through my mind and I can't sleep. Tomorrow I will do the twelfth and final interview for my study, and hear the story of another baby who died before he should have. Should, would, could... how are these decisions made, if God does play a role in how it all plays out? But that's a side story, my ongoing spiritual quest for answers.*

*“You have to let it go.” “You have to get over it.” “Resolve your grief.” Why do these concepts anger bereaved parents so much? “Of course,” the therapists and researchers and theorists would say, “of course grief must resolve in one form or another, to some extent at least – or the bereaved would become incapacitated, unable to be functioning, healthy, productive members of society.” Yes, say the parents, we do learn to live again in society so that we appear to have*

*“overcome” our sorrow. But our grief does not end. We just learn to live with it. And perhaps a small number of us don’t learn to live with it and we plunge into despair indefinitely – or into death ourselves.*

*We buried our pain, some parents say. But it didn’t go away – it was still only buried. We want to feel the pain, other parents say. It’s a part of our children who died. It’s a comfort. We want to be angry, we don’t want to release our anger, we want to hold onto it, as a tribute to and a way of honouring our babies’ lives. Our anger is justified, and the world must hear it. No, others say, we must not remain mired in grief. We must seek peace, we must make something positive come from our pain. We must not turn inward when instead we could be keeping their memories alive by helping others, and thereby helping ourselves. (Journal entry, May 2002)*

## 10. CONCLUSIONS AND RECOMMENDATIONS

*...And you will know  
the anatomy of loss so well  
it becomes a part of you  
and you will own it.<sup>34</sup>*

From the outset of this project, I have viewed my fellow bereaved parents as the experts on the experience of losing a baby. Writing the preceding chapter was difficult for me, because it seemed as though I was moving from providing a forum for hearing my participants' wise and knowledgeable voices, to assuming the role of expert researcher who must translate and interpret what the parents have said. I believe that the stories speak for themselves; they do not need any explanation. However, the chapter was important for a couple of reasons. First, I proposed to study meaning-making and self-changes from the outset of this study because of my personal experience of self-changes emerging from my attempts to make sense of my son's death; and because grief theorists and researchers have been increasingly targeting these as central aspects of grief that stand out in clinical reports and narratives of the bereaved (Attig, 2001; Braun & Berg, 1994; Davis, 2001; Miles & Crandall, 1983; Nadeau, 1998; Neimeyer & Keesee, 1998; Neimeyer, 2001). A second, related purpose of the chapter was to connect what has been learned from these parents to existing grief models, theories, and counselling practices. The parents' stories can thereby become a part of the larger bereavement research story, adding new insights, suggestions for improvements, or changes to existing theories or practices pertaining to perinatal loss, with the ultimate goal of informing and helping medical professionals, mental health professionals, social networks, and parents themselves. In this final chapter, I present a selected summary and conclusion of what I view as the most important messages and recommendations from the parents' stories, in an attempt to address more completely the second of these purposes.

### 10.1 Summary of Conclusions and Unique Contributions of this Study

#### *10.1.1 Contributions to a Meaning Reconstruction Model of Grief*

The previous chapter provides an in-depth consideration of meaning reconstruction, self-changes, and long-term grief following a baby's death, perhaps more so than any previous perinatal loss research has. A constructivist approach was the philosophical grounding for this

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<sup>34</sup> A portion of a bereaved woman's poem, quoted in Fickling, 1993, p. 229

project, with the view that the personal and unique narratives or stories that bereaved parents told represent their efforts to imbue their experience of perinatal loss with meaning. Such meaning was both contained within and influenced by the social and cultural context which parents were exposed to and embedded in. A constructivist approach was a good fit for this study, given the observation that the parents' grief involved a dynamic, lifelong meaning reconstruction process without an endpoint. Grief for these perinatally-bereaved parents was an evolving process that was informed by their continual efforts to make sense of their life experiences in general, within the context of their histories and the ever-shifting ideologies of the society and culture in which they live.

The main conclusion from the preceding chapter is that perinatal loss results in as complex a meaning crisis and meaning reconstruction process as other forms of loss. The experiences of these parents most closely resemble the meaning-making and grief of bereaved parents who have lost an older child (see Bernstein, 1998; Talbot, 2002; Tedeschi & Calhoun, 2004). A critical difference for the grief process of these parents, however, was the disenfranchised nature of perinatal loss. The loss-minimizing and dismissive responses of first the medical establishment and then the parents' social networks, particularly in past decades, served to complicate the meaning-making process and thereby stifle or exacerbate their grief.

As voiced by the parents and echoed by grief therapists and researchers (e.g., Calhoun & Tedeschi, 2001), positive self-changes or personal growth did not remove the pain and distress of grief. It is self-evident that even when parents appreciated the changes, they would have preferred to have their babies and *no* growth. Consistent with Calhoun and Tedeschi's (2001) description of posttraumatic growth, for the parents in this study finding meaning in their loss and grief appeared to be a precursor to positive self-changes, and growth tended to occur only after an initial coping success. While many of the parents in this study spoke of what could be labelled positive self-changes or growth, several others identified additional changes that were negative, or they perceived only negative changes. Other researchers have similarly emphasized that self-changes reported by the bereaved are certainly not always positive. One study, for example, indicated that 40% of their bereaved sample stated that what they had learned from their experience was not necessarily positive (Frantz, Farrell & Trolly, 2001).

The impact of the meaning-making process on long-term grief was also clear from the parents' stories. In addressing concerns about the relative lack of understanding of long-term grief outcomes after a perinatal loss (e.g., Boyle, 1997; Lin & Lasker, 1996; Zeanah, 1989), this study showed that having difficulty identifying positive meaning and being unable to come to terms with the meaning of one's loss resulted in buried or unchanging grief that lasted

indefinitely for some parents. Contrary to early studies that described such long-term grief responses as being pathological, I argue that parents whose grief was buried or unchanging were responding in a normal fashion to extraordinary circumstances (i.e., specific complicating circumstances surrounding the death combined with loss-minimizing reactions of their social world). As Attig (2002) conveyed, grieving is by definition a complicated process of “relearning the world,” and it is our normal, functional, and adaptive response to being deprived of someone we love. It is not a disease or a pathological psychological response to death as is so often implied from medical/psychiatric points of view. In the case of parents in this study who buried their grief or remained in a state of unchanging grief, their grief became complicated by special challenges and extraordinary circumstances that made it more difficult for them to respond to their losses in an effective way (Attig, 2002). The parents who described themselves as having lifelong grief for their babies even if their grief had reached a peaceful state confirmed the normalcy of a lifelong grief response to perinatal loss. That is, grief continued in an evolving way even when paired with a resumption of hope, a revised worldview, and new purpose in life.

A particularly important observation about the relationship between meaning-making, self-changes, and long-term grief was the central role of *active* meaning-making for those parents whose grief was in a peaceful/evolving state. Those who had overcome meaninglessness and identified positive self-changes spoke of or alluded to actions they took or purposeful contemplations and revisions of their perspectives that helped them to move closer to the peaceful end of the grief continuum. Andrew, for example, emphasised that his grief would have remained in a self-destructive form if he had “let it just sit there” instead of seeking help and healing through his culture. Some parents took empowering actions to assert the personhood of their babies and their role as parents to their babies, which proved to be a powerfully soothing step in their grief that pointed them toward a peaceful grief path (e.g., Mona taking her baby’s body home from the hospital; Katrina assertively voicing her opposition to hurtful actions or comments of her social network). Sharon eventually shifted her perspective to a point where she saw depression as state of being that “fuels grief,” and which a person gains some reward from and therefore is not fully motivated to seek help to emerge from. And Rachel, as a final example, spoke of grief easing with time, but only through her purposefully “working on it,” including talking to a compassionate listener, rather than burying or stifling her pain.

### *10.1.2 Contributions to Understandings of Perinatal Loss*

#### *10.1.2.1 Decade in which the Loss Occurred*

There were clear differences in the social/cultural influences on parents whose losses occurred decades ago compared to parents whose losses occurred in the 1990s or later. The

paternalistic ideology of the medical establishment and the tendency of social networks to ignore or neglect parents were aspects that were more pronounced in past decades. These social forces blocked the possibility of parents engaging in rituals that could have facilitated the meaning-making process in light of the surreal nature of the loss (e.g., making the baby's identity more real by holding the baby; having photos taken). Living at a time in history when it was unheard of to question the authority and wisdom of the medical system, these parents had to endure losses that were disenfranchised. To be treated in a fashion that would have reduced the complications of their grief (i.e., with compassion, sensitivity, and as though they had endured the loss of a child), they would have had to act as fierce advocates for themselves and their babies. It is difficult for any parent to have the strength or wherewithal at the time of loss to advocate for themselves in that manner, even in the current social climate in which questioning authority is far more acceptable than it once was. This extends to the social networks surrounding the individuals, who often disenfranchised their grief as well. Even the most assertive parents whose losses occurred more recently still found it difficult to confront friends, family, or co-workers about how they would like to be treated, and to educate them about how to deal with this kind of loss.

The greater issue on the social/medical front for parents whose losses occurred more recently was the present-day high expectation regarding lifesaving probabilities (and low infant mortality), which perhaps added to the sense of meaninglessness. Those with losses occurring in earlier decades may have questioned medical competence to some degree, but more often attributed it to the limited medical knowledge of the period. They were left with "what if?" thoughts, but such thoughts appeared to be easier to come to terms with than were thoughts of the death being readily preventable (Judi and Penny were the exception, having blatant examples of medical incompetence even for the decade their losses occurred.) Those with losses since the 1990s also had higher expectations that medical staff should be prepared for compassionate management of a baby's death. They appeared to have a greater loss of faith in the medical system as well.

Layne (2003) argued that middle-class American women having pregnancy losses since the 1980s have experienced an exacerbated sense of loss because of a contradictory set of cultural forces. Specifically, with the advent of smaller family size and a later age for women to have their first child, the shared common knowledge among women about the prevalence of pregnancy loss has decreased, leading to unrealistic expectations about pregnancy outcomes. As well, the legalization of abortion in the 1970s prompted an ongoing social debate over the existential status of fetuses. Further, with the increasing medical management of reproduction

– such as successful life-saving efforts with fetuses at increasingly early gestational ages, more effective fertility treatments, and new reproductive technologies that have contributed to viewing fetuses as patients and persons at earlier stages of pregnancy – expectant parents have come to view their fetuses as children, resulting in earlier bonding which consequently influences the sense of loss when a wished-for pregnancy ends abruptly. Layne argued that these changes in social constructions of pregnancy and foetal personhood have coincided with the ongoing social limitations placed on loss acknowledgement and support that bereaved parents are confronted with after a pregnancy loss. She suggested this leads a woman to grapple with a confused set of messages and emotions pertaining to the “realness” of the baby, her status as a mother, the realness of the event, and the legitimacy of her grief (p. 17).

I agree with Layne’s suggestion that the ability of women to make sense of the experience of pregnancy loss is complicated by social forces that first encourage bonding with an unborn baby and then fail to acknowledge the significance of the baby’s death. I disagree, however, that women’s (or men’s) loss experiences have become more complicated *since 1980* because of the various social and medical changes mentioned above. Based on the experiences of the women I interviewed whose losses occurred *before* 1980, if anything the grief they experienced was *more* complicated than that of parents with losses that occurred more recently for two reasons: first, because of the greater degree of disenfranchisement of perinatal loss in previous decades; and second, because of the ever-increasing recognition in recent decades of perinatal and pregnancy loss being deeply painful forms of bereavement requiring compassionate support.

I suspect the difference between Layne’s and my perspective is her focus on *pregnancy* as opposed to *perinatal* loss, that is, her inclusion of the full spectrum of reproductive losses from ectopic pregnancies to neonatal death. Layne’s argument was perhaps influenced largely by the experiences of women having miscarriages, for which a greater degree of variability in grief response exists than with perinatal loss. It is my belief that while there are similarities, there are also important differences between the grief brought on by early miscarriage and by perinatal loss. This is supported by the experiences of the parents I interviewed who had experienced both miscarriage and perinatal loss (both pre- and post-1980). They emphasized that while their miscarriages prompted a clear sense of loss and grief, their grief was not as deep or long lasting as the grief over their babies who died at later gestational stages or after birth.

#### *10.1.2.2 Long-term Grief of Fathers*

Unlike many previous studies of perinatal loss which suggested that a father grieves less and for a shorter time after a baby dies than a mother does (e.g., Bohannon, 1990-1991;



Dyregrov & Matthiesen, 1991; Moriarty et al., 1996), this study revealed that the grief of these fathers was intense, life-changing, and lifelong. The fathers' grief appeared to be qualitatively as intense and long lasting as the grief of the mothers, even when some of the fathers suggested that their wives' grief was greater than theirs was. The stories of some of the fathers suggested that their grief and coping style was qualitatively different from their wives' grief (e.g., hiding their tears from others, not wanting to talk about their experience, not wanting to read stories of loss, and finding physical outlets for their grief). As such, their grief might have appeared to be less intense than their wives' grief from an observer's point of view (or as measured by the questionnaires utilized by bereavement researchers), but their stories and displays of emotion suggested otherwise.

Social expectations regarding men's grief presented the fathers with an additional challenge to grapple with. For example, some of the fathers described the focus of social support as being their wives' grief, which they also felt responsible for rather than their own well-being in the early months. Some felt neglected and isolated in their grief as a result, finding few outlets for their intense emotions. Their grief was complicated by the need to reconstruct their views on what was appropriate or "normal" for them to be feeling, given the unrealistic "recovery" expectations and lack of social norms for grief in general and a father's grief over perinatal loss in particular. Some fathers, for instance, described having accepted gender stereotypes before their babies' deaths, such as the view that a man is strong if he remains stoic and emotionless in response to loss of a loved one. Others had previously agreed with the socially prescribed time limitations on grief, or the view that the bereaved should not speak of or "dwell on" their loss experience. In light of their own experiences being contradictory with these previously held views, they came to ascribe to a new set of beliefs about what it means to be a "strong" man and what is an acceptable way for a man to grieve.

#### *10.1.2.3 Disenfranchised Grief: Influence of Social/Cultural Context*

Keyser (2002) noted that in addition to the grief process of relearning the world, redefining one's identity, and finding meaning in the baby's life and death, a final component is necessary in order for a "sense of recovery to be felt. To have the meaning of their baby's life validated and their grief empathically understood by others is at the heart of healing for parents." (p. 240) Humans are social beings, and, as such, we can be greatly influenced by the social world in which we live. We might be influenced by what others think of us (real or imagined), by spoken and unspoken social ideologies and norms for acceptable conduct, and by the response of others to our joy and sorrow. Bereaved parents make or find meaning in their experiences through interpersonal contacts and comparing themselves to (and struggling against) cultural

and social norms, expectations, and definitions of grief and what is the ‘proper’ way to respond to loss. When the social response to a bereaved parent’s intense grief includes silence or comments that dismiss the significance of what has occurred, they are affected deeply and their grief can become “extraordinarily complicated” (Attig, 2002, p. 15).

In studying postpartum depression, Mauthner (2003) proposed a “relational” theory in which depressed mothers feel disconnected from the experiences of other mothers and cultural representations of motherhood. The discrepancy between their experiences and what is expected of them via cultural ideas about motherhood leaves them feeling “cut off” from their social world and unable to share their experience with others. Borrowing from Mauthner’s argument, I suggest a similar relational explanation for the impact of disenfranchising social responses on the meaning-making and grief of the parents in this study. Specifically, bereaved parents experience a “disconnection” from their social worlds when they feel the pressure to conform to cultural standards and norms of “proper” grief responses and ideas about how severe their grief should be after a perinatal loss. Parents are unable to see the intensity of their grief experience reflected in the social assumptions about this form of loss that are implicit in the loss-disenfranchising responses of their social networks. They are left wondering about their sanity in light of the dissonance between what they feel and what societal norms “tell” them they should feel; or they feel emotionally abandoned by their social networks and unable to share their experience with others. Their experience is validated by others who know grief, and is called into question by the silencing voices of their social worlds. Parents are isolated in their experience when no validation or empathy is given, and are more likely to become entrenched in buried or unchanging grief.

Some parents who took a more active approach in response to the dissonance of their experience with the social prescriptions for their grief engaged in hierarchy of grief comparisons, attempting to establish the significance of their loss by defining it as more difficult than other forms of loss. Other parents voiced their anger at insensitive treatment in hospitals, at comments made, at being neglected by friends and family. These “silenced voices speaking out” are a reflection of the shifting social mentality about the emotional significance of a baby’s death for parents. They represent the strengthened response parents have been able to make in recent years because of the increased recognition of the significance of their losses.

Ultimately, the power of a supportive response from medical and social networks was to ease grief but not take it away. On the other hand, a silent or loss-minimizing response from these potential sources of support served to exacerbate grief and make positive meaning reconstruction far more difficult. Positive experiences with the medical system and social

networks opened a channel for grief expression, processing the story, and constructing new meanings. Parents were therefore confronted with one less challenge to grapple with as a part of their grief. Perhaps the most important conclusion is that *in the absence of sufficient social support and compassion, it was essentially guaranteed that these perinatally-bereaved parents would descend into buried or unchanging grief*. And in order to emerge from a state of buried or unchanging grief, they needed to first recognise and disentangle themselves from the voice-silencing, loss-disenfranchising social-cultural forces in which they were embedded simply as a function of being members of society. Doing so was far more likely if they were able to find or happen upon an empathetic companion to accompany them on the journey.

#### *10.1.2.4 General Social Ideologies*

Not all of the medical and social responses that parents encountered were linked specifically to perinatal loss being seen as less significant than other forms of bereavement. Some responses were related to social ideologies in general, or a lack of social norms for responding to grief in general, rather than being about perinatal loss as such. Dyregrov (2003-2004), for example, used the term “social ineptitude” to refer to the difficulty of bereaved persons’ social networks in knowing how to respond to situations of loss and grief. In western society, many people find it difficult to know how to communicate and support the bereaved in a way that is helpful because of a lack of available norms for how to respond in such encounters. Like grief-disenfranchising social responses, a lack of norms for responding to grief left parents wondering about their sanity, or left them feeling abandoned by those closest to them, having no outlet for their grief from expected sources. Other social ideologies pertaining to grief in general, which affected parents in their grief, included assumptions about how long a person should grieve (even when the loss is recognized as significant), and ideas about appropriate ways to grieve (e.g., that a person should not “wallow” in their grief by reading stories of loss).

#### *10.1.3 A Non-traditional Approach: A Researcher’s Personal Experience*

##### *And Evocative Narratives of Perinatal Loss*

*Reading a person’s raw, emotional, confessional tales resonates and reveals so much truth about what it is to be human, about natural human reactions, emotions, behaviour – psychology – and in a much deeper way than more traditional, “objective” research projects can reveal. I’m not saying that the only useful research reveals and exposes the researcher’s and participants’ raw emotion and most private thoughts. But, if a researcher is willing and if the topic lends itself to personal reflections and revelations, then a wealth of deeply meaningful and resonant knowledge and understanding about human emotional experiences can be achieved that otherwise could not be. The problem, though, is that the reader, particularly those that know the researcher, may feel like voyeurs – learning far more about the researcher’s innermost thoughts and anguish than they feel comfortable knowing. (Journal entry, April 2001)*

What has the inclusion of my personal experience added to this study? What has entering into the experience as understood by the parents themselves taught us? What is the value of having presented the five stories as evocative narratives rather than smoothed transcripts or selected excerpts? Janis Keyser (2002), a perinatally-bereaved mother and perinatal loss researcher, eloquently answers some of these questions:

Some of our most meaningful learning can occur by our empathic listening, taking their stories in, and allowing their meanings to resonate within us. It is through this process that we can gain a sense of the remarkably rugged terrain of parental grief after a baby's death. And as we learn to vicariously walk the territory with them, letting them be our teachers, we build the capacity to more fully understand and support them through this most difficult of times. We then become witness to the resiliency of the human spirit which can accommodate to and even grow through deep psychic pain to emotional renewal. (p. 229)

Like Keyser, I believe that presenting parents' complete stories in an emotionally compelling style brings to life the lived experience of perinatal loss, and it provides us with an empathic understanding that could not otherwise be gained. As Ellis (1995) argued, social scientists

can touch on the complexities, ironies, and ambiguities of living *only* by showing the bad as well as the good, what has been private and confidential as well as what is public and openly accessible, what makes us uncomfortable as well as what makes us comfortable. (p. 3)

Rather than categorizing, generalizing, and abstracting from brief excerpts of the stories as I did in chapter 9, presenting the five stories fully and evocatively was intended to move the reader closer to the "lived particulars" of the experience of losing a baby (Ellis, 1995, p. 4). A measure of the "validity" of evocative storytelling, Ellis suggested, is whether it evokes in the reader "a feeling that the experience described is authentic, that it is believable and possible"; and its generalizability can be judged by whether it resonates with the reader's own experiences (p. 318). I have offered *my* interpretation of the meanings of the parents; the ultimate test of the value of presenting the five stories evocatively is whether the stories stimulate in readers *their own* new meanings, perspectives, and interpretations of the experience of losing a baby.

The stories also illuminate a greater number of issues inherent to a perinatal loss than I was able to elaborate on within the scope of this project. Although I focused on meaning reconstruction in my interpretation of the stories, the stories themselves provide the reader with a richer understanding of the broader spectrum of experiences that a perinatal loss encompasses – such as relationship difficulties and marital issues that arise after a baby's death, the fears involved in subsequent pregnancies, issues specific to varying forms of perinatal loss (e.g., twin loss, stillbirth, birth defects), contradictory and conflicted emotions brought about by circumstances of the loss, and so on.

Another valuable aspect of the stories is their breaking of the silence that has previously enshrouded the experience of a baby's death. As so many of the mothers whose losses occurred before 1980 conveyed, speaking of their losses was taboo. And the silencing still exists, albeit to a lesser degree, in the present day. The stories, then, initiate the conversation and sharing that many bereaved parents have so desperately needed in order to make sense of their experiences and come to a place of peaceful grief. For the parents, the stories allowed them to voice their often previously unspoken pain and offer their experiences as a gesture of support to others bereaved of a baby. For others, the stories prepare them to become aware of the depth of the experience and move toward support of grieving parents that is more humane, compassionate, and empathically informed (Bochner & Ellis, 1996).

Finally, to return to the opening question of this section: what has the inclusion of my personal experience added to this study? What it *has* added is up to the reader to decide. What it was *intended* to add was a revelation of my subjective experience, both as an additional example of the lived experience of perinatal loss, and as a reflection of how my experiences might have influenced my presentation and interpretation of the parents' stories. What it has added to *my life* is a more deeply conscious understanding of my grief over my son's death.

## 10.2 Recommendations

What can be done to support parents bereaved of a baby, to ease their grief? What changes need to take place in order to reduce the harm done to parents through encounters with their social worlds? How can we help parents to reach a place of peaceful grief rather than buried or unchanging grief? The following recommendations are a blend of my thoughts and the parents', with the goal of showing professionals, social networks, and other bereaved parents what would "make a horrible experience just a little easier," as Sonya expressed.

### *10.2.1 Medical Professionals and Therapists/Counsellors*

While some of the recommendations listed below have already been adopted by hospitals throughout North America, most of the comments came from parents whose losses occurred within the past 10 years, suggesting that further changes need to be instituted. I have therefore included both new recommendations and ones that have been adopted within many locales.

#### At the time of the baby's death:

- Parents recommended that hospital staff take good quality photos, since few had more than one or two Polaroid photographs, which were sometimes of poor quality. As well, a checklist of items to collect (e.g., handprints, footprints, a lock of the baby's hair) should be followed closely to give parents as many tangible mementoes as possible. They also suggested that

hospitals follow a policy of giving parents explicit guidance during the hospital experience, so that they have no regrets later on. Such guidance should be sensitive yet directive, since parents are often unable to foresee the issues they might have regrets about weeks or months later. For example, medical professionals involved during the time surrounding the death should:

- suggest that parents take additional photos with their own camera
- recommend that parents invite family and close friends to see the baby
- inform parents that they can spend as much time as they want with the baby
- offer for parents to dress and bathe the baby
- give preliminary advice for funeral arrangements

In the weeks and months following the baby's death:

- Parents appreciated postpartum nurses who made a point of visiting after the baby's death (even though that was not their mandate), and who were comfortable with "just listening" but also being prepared and educated about grief and the chaotic emotions that parents can feel (e.g., Stacie appreciated the nurse who validated her right to be angry, to feel cheated, and to be angry with God).
- Irene suggested more education about grief for health care professionals – in the broad sense of professionals recognizing the importance of touching and comforting patients in a compassionate way, showing warmth and a human connection.
- Also suggested was a revision of grief pamphlets and procedures for introducing newly bereaved parents to grief concepts, avoiding suggestions of "stages" and an endpoint to grief. They also felt there should be a health-care follow-up (conditional on the parents' consent, but strongly encouraged) by a professional who is well versed in the most recent grief theories, the grief of parents, and issues specific to perinatal loss. Some parents spoke of the value of talking to someone who has "been there," such as a peer counsellor.
- Regarding family physicians and obstetricians' roles in the postpartum period, Sonya mentioned that her physicians made arrangements so that she would not have to wait in the waiting room and be surrounded by pregnant women and babies. They also booked longer appointments for bereaved parents; made allowances for unscheduled visits; took time to ask about how the woman (and her husband) is doing psychologically as well as physically; and booked appointments at a time of day that was less busy or in which it was less likely that pregnant women and children would be in the waiting room. Physicians should not expect the mothers to ask for these special allowances, but they should be made a part of standard procedure. It should also be clearly noted on charts that this woman had a perinatal



loss so that other professionals do not ask painful questions repeatedly. As well, physicians should avoid sending the woman back to the hospital where her baby died too soon afterwards (or at least check with the mother about her preferences). Physicians should also have suggestions for reading literature specific to this type of loss that helps the parents feel less alone and understand what is normal.

- The importance of concrete answers about the baby's death was clear in all of the parents' stories. Other research has similarly demonstrated the importance parents place on concrete explanations for a baby's death in helping them to make sense of their experience (e.g., Dunn, Clinton Goldbach, Lasker, & Toedter, 1991). In terms of recommendations for physicians, any concrete explanation for the loss, even if tenuous, can help to give parents a sense of meaning and order in a world suddenly experienced as chaotic. However, even when given alternative explanations, some mothers continue to hold themselves responsible for the loss. As Dunn and colleagues (1991) found, mothers often believe they had some control and are therefore blameworthy, even when aware of alternative biological explanations. Grief outcomes can be substantially more problematic when self-blame is directed at one's character rather than one's behaviour (e.g., viewing self as a failure as opposed to viewing the death as being a result of some action that could be reversed, such as being exposed to excessive stress during pregnancy). As Judi's story demonstrated, parents who engage in self-blame are more likely to have negative long-term grief outcomes. It would therefore be helpful, first, for physicians to work towards preventing such self-blame by recognizing and addressing the intense need for answers; and second, to openly discuss self-blame tendencies in the early period of grief in order to help parents in releasing themselves from self-blame meanings.
- Sonya also had a warning about suicidal thoughts and plans, particularly on the part of newly bereaved mothers (it should also be considered for fathers, and in the longer term as well). She said that she had a suicide plan in place and came very close to following through and no one knew, despite doctors directly asking her (she simply denied it):

...the risk of suicide, the inner turmoil that would push you to that level, is horrific. And, just to be aware of it, and the patient's not going to tell you. They're not going to give you the signs, they're going to hide it. And I know my doctor would ask me questions, but.. she didn't know. She had no clue, so just be very cautious of what [medications] you prescribe the patient. And don't let it sit at, "No, I'm not having those thoughts." I did see a counsellor by myself several times. She picked up on the suicide issue, I must say. But.. I don't think she understood how serious it was. She sort of missed out on that one. 'Cause she did get me to promise that I wouldn't do it, and it's like, {said with a small laugh} "Yeah sure, I could promise you but you have no concept! I'll promise you anything right now, but.."



During subsequent pregnancies:

- With respect to subsequent pregnancies, medical professionals should be sensitive to the anxiety and fear that parents go through during a subsequent pregnancy, and act accordingly. For example, they might order extra tests if that is what gives parents reassurance and peace of mind. The emotions involved in trying to conceive again must be understood, and that these expectant mothers need their minds to be put at ease more than do other pregnant mothers. As Sonya expressed: “And health care professionals, again, understand that even a very intelligent, logical woman can have very irrational thoughts. I mean, I know the medical side of certain things, and even then, I have really bizarre [thoughts], “oh my God, what about this?!”
- Also recommended was a service such as a telephone support line available to mothers having a pregnancy subsequent to loss, in order to help them through the inevitable moments of panic. Another possibility would be a pregnancy-after-loss support group, which are becoming quite common in the United States (see Coté-Arsenault & Freije, 2004).
- The common practice of professionals citing low odds for the risk of a subsequent baby dying was something Sonya felt was *not* helpful:

With us it was a 2% chance [of recurrence], but even then, I mean, [I feel], “Don’t tell me odds anymore.” I mean, that’s what they’re saying, “Odds are, this..” And I’m looking at them going, ‘I’m sorry, but I had very slim odds for this happening the first time, so don’t give me odds to reassure me that this is not going to happen again.”
- Physicians in the position of offering genetic testing need to recognise the implications of such testing for parents who are grieving for a baby with genetic birth defects. In many instances, such recognition might translate into *not even suggesting the possibility of genetic testing*, trusting instead that because of their history, the parents are well aware of the options but would rather not hear the implication that their deceased baby “should have been an abortion”, as Sharon put it. In other words, when the only possible courses of action from a positive test result (i.e., indicating that the baby from a subsequent pregnancy has a genetic syndrome) are to continue or terminate the pregnancy, the value of such testing is highly questionable when dealing with parents who are more likely to take offence at the suggestion than draw any comfort or reassurance from a negative test result.
- Finally, medical professionals should have training to deal with grief that emerges in mothers (and fathers) during subsequent pregnancies. Sonya’s experience was that some dealt with her expressions of grief insensitively, while others ignored it and appeared to hope it would go away because they did not have the knowledge or skills to deal with it. They should also

understand that there is not a predictable timeline or endpoint to grief over this or any other type of loss, and that grief overlapping with the joy of having another baby is normal.

In the longer term:

- Some parents said that they would have attended support groups if one had existed for perinatal loss specifically. Their awareness of perinatal loss being seen as less significant than the loss of an older child left some feeling uncomfortable attending support groups for bereaved parents in general (such as The Compassionate Friends); others felt a kinship with other bereaved parents, but felt they would be uncomfortable discussing the unique issues of perinatal loss with a group designed for parents bereaved of an older child.
- Irene noted that her loss was never unearthed in her health and mental health care encounters over the years (including psychiatrists, drug/alcohol rehab counsellors, family physicians). The topic was never broached as being a part of her struggle with depression, despite the fact that it was, as far as she knew, in her medical history (i.e., when asked how many pregnancies she had and what the outcome was she would have mentioned her baby that died, and this information would therefore have existed in her medical charts). She was also disappointed that the rehab centre that she went to was excellent in terms of substance abuse treatment, but when she asked to see a psychologist she was told she “wasn’t sick enough, or it wasn’t their mandate”. As she said, “you have to find the source. Addictions don’t just happen... there’s many people who it’s only a symptom of many underlying things.” To further Irene’s point, I suggest that medical and helping professionals must be mindful of the possibility of self-blame and shame being the root source of extraordinarily complicated grief in parents, as Judi’s story demonstrated.
- Counsellors should have knowledge of the unique challenges presented by a perinatal loss. They should also understand that the grief of parents does not follow a simple stage model of grief, but can be as complex, evolving, life-changing, and life-long as for parents bereaved of an older child. Parents might attend counselling for reasons other than their loss experience, but they might mention their baby’s death during sessions. A careful questioning of how they feel they have dealt with the loss might reveal that their grief is an ongoing issue for them. Whether initiated by them or unearthed in the course of therapy for another issue, a few points should be kept in mind. First, parents might need to be invited to grieve, given that the primary message they might have received over the years was that their loss was insignificant and they should simply forget and have another child. Before they can uncover buried grief, they might need validation that what they experienced was a significant loss. Second, from a meaning reconstruction perspective, counsellors must understand that the

meanings parents arrive at to explain their experience are personal and unique, rather than being readily predictable and universal. Meanings are influenced by a person's distinct circumstances, characteristics, and social/cultural contexts. As such, two people experiencing very similar loss circumstances can come to very different meanings and have a very different long-term grief outcome (Neimeyer & Keesee, 1998). The counsellor's role, in this view, is to help the parent identify, elaborate, and negotiate the meanings that they have ascribed to their experience and that have influenced the trajectory of their grief (Neimeyer & Raskin, 2000).

#### *10.2.2 Social Networks*

- Parents were very grateful for help received from family and friends with difficult funeral arrangements (e.g., buying clothing for the baby to be dressed in at the funeral). Sonya noted her appreciation of a funeral home worker who compassionately suggested that she would be helped in her grief if she dressed her baby for the funeral herself.
- Some parents mentioned feeling compelled to support family members who displayed intense grief over their baby's death, which was not at all helpful during their most intense grief. As Mona conveyed: "at some points I felt like I was supposed to be the strong one to help *them* get over it. Which was very odd... you know, they kind of came to us for support for *them*."
- Others mentioned being comforted by family members, friends, medical personnel, and clergy who openly showed love and sorrow for their babies in the hospital or at the funeral (i.e., not holding back their tears).
- Family and friends should select an appropriate time and place if initiating a conversation about the baby's death and the parent's grief – not in a public place, for instance. (Mona's example was a wedding).
- Some parents said that what was most helpful was having a friend or family member who was willing to listen and be comfortable with the intensity of parents' many emotions – grief, anger, despair, trauma, outrage, isolation, devastation, agonizing sorrow – without trying to "make it better". Even decades later, having compassionate and insightful family or friends to talk to about the loss was greatly appreciated.
- Family and friends should make a point of remembering the baby with the parents beyond the early period, in particular by acknowledging birth and death anniversaries, special holidays, and mother's day and father's day (especially for parents with no living children). Sonya, for instance, had a friend who found a mother's day card that was designed for mothers in her situation (childless parents). Parents appreciated it when others uninhibitedly

spoke the baby's name, not hiding, denying, or ignoring their existence. Cards and phone calls were also viewed as helpful, including actually speaking about the baby (i.e., not just phoning to chat and avoiding any mention of the baby).

- Employers' responses: Some mothers spoke of the importance of women being able to take time off with pay. Some went on short-term disability, or were able to collect maternity benefits. Fathers' ideas about the necessity to return to work were more variable. The fact that some wished they had more bereavement time (with pay) available to them suggests that this is something employers should consider.
- Friends and family should make a point of including the father in any supportive gestures, rather than only asking about and focusing on the mother.

#### *10.2.3 Fellow Bereaved Parents*

- Some parents mentioned being helped immensely by journal writing. Bill, for example, said that, "putting all of this on paper was the *only way* I could *deal* with it. But I could only write for half an hour at a time." Talbot (2002) noted the value of journal writing or "scriptotherapy," as well as "bibliotherapy," which refers to reading grief literature or writings by other bereaved people as a way to understand one's grief, validate that one's feelings are normal, and experience emotional release. Several of the mothers in this study noted that bibliotherapy was helpful for them. The literature most often noted as helpful was self-help literature which focused on pregnancy and perinatal loss (especially those written by fellow-bereaved parents), as well as stories and other literature available on internet websites dedicated to pregnancy and perinatal loss. Some parents mentioned needing to approach these resources with caution as, for example, when a particularly religious (usually Christian) approach that does not fit for everyone is the basis for the writings. See Appendix F for a selected list of books and websites that some parents found helpful.
- Several parents noted the value of speaking to fellow-bereaved parents (particularly with similar circumstances) in order to validate the normalcy of their grief response.
- In the acute period, some parents mentioned the value of focusing on doing something positive rather than focusing on the grief (e.g., Bill making his daughter's coffin; preparing details of the funeral service to make the baby's individuality more real for oneself.)
- Recognize that you have the right to feel bad for yourself, the right to be angry. Know that grief is a long and difficult process and your grief will likely continue in some form throughout your life, but finding peace with your loss and a love of life is possible again, even if you are forever changed.
- For those who are having a subsequent child, recognize that you are still grieving, but it can

be a healing/soothing experience as well. It can help you to feel physically redeemed if you felt betrayed by your body before. Realize that a subsequent pregnancy is going to be terrifying at times, with irrational thoughts that need to be dealt with, maybe even more so if the baby who died was stillborn. As Sonya said,

I think for women who are going into the subsequent pregnancy, just to be aware of it, and it's okay. Just talk about it, and try to talk your fears away, and go see your doctor as often as you possibly need to if that's what it takes you to get through it. And go to a physician who is going to give you that time, and get you in when you're feeling panicked and stressed.

- Some parents believed they survived by having a sense of humour, as Penny expressed:

I have a sense of humour, and I will laugh at a lot of stuff.. to cover up... that's always been the way I've dealt with things. And then, on the other hand, I've often said I'm glad I have my sense of humour. 'Cause if somebody says, "Well how did you manage?" I say, "Well.. especially after my divorce, some of the things that I think back that I said.. I laugh about it now, and you know, if I wouldn't have had my sense of humour, I would never have survived." Maybe in a way.. it wasn't the right way, but to me, for me, that's what helps me.

- Recognize when you need to find someone to talk to about your experience, especially if you have never or rarely had the opportunity to tell your story. Some mothers found a compassionate place to talk about their grief by becoming involved in counselling, either on an individual or group basis. Penny described her experience at a series of counselling workshops:

I took two workshops. And it was the second workshop, where I had to, for the first time, talk about all this. And then I went back for counselling, and it was very helpful. That's the first time I could--, and I had a lot of guilt. I used to blame myself for everything. So we worked through all that. And it was just like.. a big load had been lifted off me. But you know, to have waited all those years. I think it was 6 years ago [about 20 years after her third baby died].

- Do what you need to for yourself in terms of talking about the baby or making his/her existence known to others. For example, when asked, "How many children do you have?", or "Is this your first one?" when pregnant with a subsequent pregnancy, others might become uncomfortable if you are honest and mention the baby that died, but that is for them to deal with, not you. The same is true for issues such as deciding when to put the baby's things away, and who should do it. Parents emphasized that you should not feel pressured by others' opinions on what is "normal," but honour your feelings and needs.
- Include the baby in special occasions through ornaments or some meaningful object or ritual (e.g., making a donation in memory of your baby, planting a tree, buying a Christmas ornament).

- Collect and create something tangible and personally meaningful to help you memorialize your baby. Doing so can also help to show others how real and important your baby was to you, as Christine said about memorial cards she designed and sent as a thank you after her baby's funeral: "It helped me heal, as I went through each one... it showed [others] that this girl was real, to make them not forget. That this little girl was a real person, even though she was with us such a short time." Such memorial items or rituals can become a part of your yearly tribute to your baby on the anniversary of his/her death. For example, Sharon wrote a tribute to her daughter each year that she sent to close friends and family; Mona involved her preschool daughter in remembering her baby through a children's book that was personally meaningful and helped in discussions about death.
- Irene pointed out that a person does not have to continue working with counsellors or other health care professionals who they do not experience as being helpful. As she conveyed:  

I decided that, *no*, I don't have to listen to him or her, because they're *not* on my wavelength, and they don't understand me. Whether that be a priest, a social worker, a doctor.. They're *not* better than I, they *don't* know better than I, *only* I know better than I about me. And so I'm only going to take the help from the people who are *helpful*, rather than~.. And I've learned to make those decisions.
- Some parents spoke of helping themselves by attempting to educate their social networks about their needs as they grieved, including letting others know that discussion about the baby was welcome. In studying the response of social networks, Dyregrov (2003-2004) noted a similar self-help approach. The bereaved themselves were often able to take the supporters' point of view, recognizing and sympathizing with the difficulty the supporters had in knowing how to be supportive. Like some of the parents in this study, they mentioned that one coping mechanism that helped them was "openness" when dealing with social ineptitude – "frankness, honesty, and directness in interaction with others" (p. 34). They achieved this through finding opportunities to tell their story of loss and other aspects of their experiences to people in their social circle; informing others of the event, thereby initiating dialogue and communicating frankly about the loss and letting them know that discussion was welcome; and explicitly informing them of how to be supportive (e.g., clarifying what their needs were).

### 10.3 Personal Reflections and Future Directions

*Each of the stories told to me from these bereaved parents' hearts touched me in a different way than the last. Each gave me new meanings, new ideas and emotions to contemplate and store away in my mind and soul. Each of them taught me something new, soothed me, comforted me. Telling their stories was one of the ways the parents attempted to make sense of their grief and loss, as this project was for me. Sharing our stories was a form of therapy for some of us, as well as our offer of understanding and compassion to other bereaved people who will read our stories. And likely, for many of us, the sharing of our stories was for our babies as well - a*



*legacy, a self-defined “reason” for the tragedy. Sometimes the sharing has been a way of creating something positive out of our pain. Our stories also portray the reconstruction of our lives in the midst of the storm of grief. Sometimes the reconstruction was messy, haphazard in appearance, not very sturdy or stable; other times it was rebuilt like a war-fort, an impenetrable barrier to outsiders. And sometimes, the reconstructed life had new features that were an improvement on the old. (Journal entry, July 2002)*

In the end, this project has become a part of my story of losing my son. What I have chosen to focus on is, in many ways, a reflection of the issues that I have grappled with, such as the social response to a baby’s death, or my (sometimes unconscious) desire from the beginning to “prove” that perinatal loss is a significant, life-changing loss involving life-long grief. In the pages of this dissertation I have revealed and become aware of several inconsistencies in my thoughts – such as feeling anger when different forms of loss are rank-ordered, yet on a personal level reacting very strongly when the suggestion was made that infertility is as difficult as my loss. I have engaged in this rank-ordering in other ways as well, such as arguing that research showing short-lived grief among people experiencing pregnancy loss is confounded by including miscarriage with perinatal loss (implying that I think miscarriage is not as difficult as my experience of stillbirth); yet I have also made comments that suggest perinatal loss is as difficult, and perhaps even more challenging in some respects, as the loss of an older child. I am not retracting my comments or arguments, but simply reflecting on the inevitable influence of my emotional subjectivities on the focus of my interpretations and conclusions.

At various points in the process, this research has prompted new questions for me. What is the process by which some people show more resilience than others in transcending loss and grief? What is the qualitative difference in their overall life stories that helps to explain greater or lesser resilience? What are the perspectives of health care professionals, friends, and family members when patients/loved-ones experience the death of a baby? What do their stories tell us about the social side of the experience? In 10, 20, or 30 years, what will the long-term grief be like of parents whose losses occurred recently, in the time since the shift in society’s and the medical establishment’s understanding of and response to perinatal loss? Future research focusing on such questions could further knowledge and theory about grief in general or perinatal loss in particular.

In her anthropological study of pregnancy loss, Layne (2003) commented on how her personal narrative of multiple pregnancy losses was inevitably changed through her research: “as is so often the case, the exchange went both ways, and I have found the images and symbolic vocabulary of pregnancy-loss support groups working their way into my personal narrative of loss.” (p. 8) Like Layne, my story and my *self* have been forever changed by the



experiences and perspectives of the parents who told me their stories. What would my grief have been like, these 6 years later, if I had not done this research? While that question is unanswerable, I know that as difficult as it has been at times, listening to and writing about these parents' stories has helped me to grow in ways that would not have occurred otherwise. I have grieved with them and found hope through them.

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## APPENDIX A: RECRUITMENT MATERIALS

The following advertisement was sent out as a public service announcement to a number of provincial newspapers, as well as printed in the “Campus News” column in the Saskatoon Star Phoenix (Friday November 30, 2001, Page A12), by Tina Merrifield (Office of Communications, University of Saskatchewan).

Myrna Willick, a PhD student in the psychology department is doing a study on the long-term grief experienced by men and women who had babies die during late pregnancy or shortly after birth. The purpose of the research is to learn more about how parents deal with, and are affected by, this type of loss over the years.

Willick, a bereaved mother herself, invites men and women who have experienced this type of loss – recently or years ago – to tell their stories in an in-depth, one-on-one interview.

Interviews will be done at a location that is convenient for participants. If you are interested in learning more about this study, contact Myrna at [phone number and e-mail address].

A second advertisement was placed in the Saskatoon Sun (Sunday February 17, 2002).

A Ph.D. student in the Department of Psychology at the U of S is doing a study of the long-term grief of men and women who had babies die during late pregnancy or within the first month of life. The researcher, a bereaved mother herself, would like to invite men and women who have experienced this type of loss, ranging from one year to several decades ago, to tell their stories in an in-depth interview. If interested, contact Myrna Willick at [phone number and e-mail address].



## APPENDIX B: INTRODUCTORY LETTER

My name is Myrna Willick, and I am a Ph.D. student in clinical psychology at the University of Saskatchewan. I am doing a qualitative study of perinatal loss (which includes stillbirths and neonatal deaths) in order to gain a better understanding of how parents who lose babies in this way make sense of their loss over the years. I have a personal connection to this topic, having had a stillborn baby in September of 1999. I made the decision to do this study with the hope that it might help other people who have had this type of loss, as well as the professionals who work with them (such as, doctors, nurses, funeral directors, clergy, and therapists).

The study will involve doing one-on-one interviews with women and men who have lost a baby through stillbirth or neonatal death. I am interested in interviewing people whose loss happened at least one year ago (with no upper limit), because very little is known about grief beyond one or two years. Some people who have lost a baby welcome the opportunity to talk to someone else about their baby and their loss because they don't often get the chance. Losses that happened 15 or more years ago were often handled very insensitively in hospitals, and these people sometimes find it particularly helpful to have the chance to tell their story after many years.

During the interview I will ask people to tell me their stories in whatever way they would like. I am particularly interested in how their grief changed over time, whether (and how) they were able to make sense of their loss and resolve their grief, and whether the death changed them or affected their views and beliefs over the years. I will also invite people to share mementos, poems, and journal notes about their experience if they would like to.

If you are interested in participating in this study, we would meet for a 2-3 hour audio-taped interview either at your home or at an interview room on the University campus, whichever would be more comfortable for you. Some time after the interview I would give you a copy of the transcript of our interview, and if you would like, we could meet again for you to give me your feedback, comments, and any other thoughts that might have had after the interview. If you decide to participate, I will be sure to keep your identity confidential – that is, I will not use your name or any other details that would allow other people to identify you.

Thank you for your interest in this study. If you have any concerns or questions or would like to participate, please call me at [phone number and e-mail address].

Sincerely,

Myrna Willick

## APPENDIX C: DEMOGRAPHIC INFORMATION

Name:

Phone number(s):

Address:

Age category (less than 25, 25-35, 35-45, 45-55 etc.):

When the loss occurred:

Marital status:

Other children/sequence of births:

Years of education:

Occupation:

General standard of living:

Other losses besides the one being discussed:

## APPENDIX D: INTERVIEW GUIDELINES

1. The pregnancy, significant aspects of it relevant to the death and their response
2. Details of the death and immediate events surrounding it (e.g., hospital experience, seeing the baby, time spent with baby, mementos, ceremonies; information about the cause of death, autopsies performed, etc.)
3. Social support/ response of others; Support over the years? Do you ever talk about the loss or your baby now?
4. Marital/partner relationship
5. Family relationships/other children
6. Religious meaning-making issues (e.g., What is (is there) the spiritual side of your loss, your spiritual views? Have these beliefs been changed or come about because of your experience?)
7. How do you view your loss? Was it something that had a great impact on you?
8. Anniversary reactions? How have you dealt with your grief? (If important to you) Have you found a way to include your baby in your life now?
9. How has your grief changed over time? Has it “resolved”?
10. How have you made sense of your loss? Have you? (If not) how do you understand your difficulty? (If yes) what helped you to do this?
11. Any Life lessons/truths that have come out of your experience? Have you experienced any changes/transformations? How do you view the world now (if differently)? How has your baby’s death influenced your perspective on life, your values, your relationships, and so on?
12. Any experiences that greatly influence how you have (or have not) made sense of and come to peace with your loss?
13. Other thoughts/experiences not discussed about your experience; or things that influenced your experience of losing your baby?

Close the interview by assessing how they feel after having gone through the interview process? What did they expect from the interview, and has anything about the interview or their response surprised them? Did the interview bring up painful feelings that they feel they need help dealing with? (Refer to a counsellor, offer support materials)<sup>35</sup>.

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<sup>35</sup> Adapted from Nadeau, 1998

## APPENDIX E: TRANSCRIPTION CODES

Some of the following codes are mine, some are adapted from Poland (1995):

Short utterances by a speaker within the other speaker's lengthy speech: denoted by double parentheses. For example: "so that's where I was at ((mmhm)), and.."

Questioning sound at the end of a sentence: not meant to be a question, but questioning intonation (in terms of asking listener if they understand). Indicated by (?)

Partially spoken or stalled word: indicated by two hyphens (e.g., "my fa-- my family")

Pauses: short pauses during talking are denoted by a series of dots (...), with more dots indicating longer pauses.

Coughing, laughing: indicated in parentheses: e.g. (cough), (deep breath), (laugh)

Interruptions: a person's speech broken off in mid sentence is indicated by a hyphen (-) at the point where the interruption occurs (e.g., what do you-)

Overlapping speech: hyphen indicates where one speaker interjects into the speech of another, with "overlapping" in parentheses

Garbled speech: if guessing what was said, word is placed in square brackets with a question mark (e.g., [doubled? glossed?]). If indecipherable, this is denoted with [inaudible] and the approximate number of words (e.g., [inaudible x 3 words])

Emphasis: emphasis on a word is denoted by italics, strong emphasis by all caps

Held sounds: e.g., "No-o-o-o, not exactly"

Paraphrasing others: denoted by (mimicking voice) followed by quotation marks

Researcher's descriptions or explanations: indicated by squiggly brackets {}

## APPENDIX F: SELECTED PERINATAL LOSS LITERATURE AND WEBSITES

### Literature (books and booklets):

Fackler, T., & Kik, G. (1999). Threads of hope, pieces of joy. A pregnancy loss bible study for group or individual use. Madisonville, Kentucky: American Printing Company.

Ferguson, D. (1989). Little footprints: A special baby's memory book. Omaha, NE: Centering Corporation.

Fritsch, J., & Ilse, S. (1988/1997). The anguish of loss: A grief journey of love and hope. Maple Plain, MN: Wintergreen Press.

Fumia, M. (2000). A piece of my heart: Living through the grief of miscarriage, stillbirth, or infant death. Berkeley, CA: Conari Press.

Ilse, S. (1996). Empty arms: Coping with miscarriage, stillbirth and infant death. Maple Plain, MN: Wintergreen Press.

Lothrop, H. (2004). Help, comfort, and hope after losing a baby in pregnancy or the first year. Cambridge, MA: DaCapo Press.

Limbo, R. K., & Wheeler, S. R. (1986). When a baby dies: A handbook for healing and helping. La Crosse, WI: Resolve Through Sharing.

Powning, B. (1999). Shadow child: A woman's journey through childbirth loss. Toronto, ON: Penguin Books.

Schwiebert, P. (1996). Strong and tender: A guide for the father whose baby has died. Portland, Oregon: Perinatal Loss.

### Websites:

1. A Place to Remember: [www.aplacetoremember.com](http://www.aplacetoremember.com)
2. Babysteps: [www.babysteps.com/index.html](http://www.babysteps.com/index.html)
3. Honored Babies: [www.honoredbabies.org](http://www.honoredbabies.org)
4. Hygeia: [www.hygeia.org](http://www.hygeia.org)
5. Kota Press: [www.kotapress.com](http://www.kotapress.com)
6. SANDS: [www.sandswa.org.au](http://www.sandswa.org.au)
7. SHARE Atlanta: [www.shareatlanta.org](http://www.shareatlanta.org)
8. Stillfathers: [www.stillfathers.org](http://www.stillfathers.org)

## APPENDIX G: SAMPLE TRANSCRIPT (UNSMOOTHED)

{The tape was turned on after a brief discussion about the study and signing of the consent form signing. Note re: emotion: Deena's emotion was not audible, but at several points while she spoke her eyes welled up and her face flushed, and she was obviously experiencing some deep emotions at times}

Myrna: So um, so I decided to do this research 2 years ago, I decided--, made the decision, and I started it two years ago. Um.. my son.. died, he was stillborn, um, 2 years and 3, 4 months ago, whatever, in September of 1999. And so.. I was in the middle of doing my Ph.D. in Psychology, and I was kind of in the middle of changing supervisors, too, for my research. And so when this happened, all I could think about--, like I decided, okay, I'll go back to school after three months, three months after he died,.. um, and I decided.. that, you know, I'm going to be thinking about this all the time anyway, why don't I do research on it, and, try to make something come, come out of this, you know ((oh yeah)) And so.. and I also found it very helpful to be doing a lot of reading and, you know, reading other people's stories, and reading about (deep breath) the research that is out there, and what is already known about how people grieve this kind of loss. (deep breath) And I found myself becoming really.. unsatisfied with what has been done already(?) There's been a lot of focus on um... how people.. end up in really bad shape(?) And a lot of focus on women, and no talk of men at all. And so I decided I wanted to hear what--, hear from, from people who'd had this experience themselves. I want to hear from... (deep breath) from parents how--, what matters to them, what mattered about that experience ((mmhm)) What--, let them, rather than me asking a bunch of questions, let you guys tell me what mattered about that experience, and what was important and... Um, 'cause researchers tend to have all these ideas, and these questions and stuff (((soft laugh))), and sometimes it seems pretty meaningless what they come up with, and, it doesn't seem very helpful to anybody. So I thought, you know, if I do it this way, so that I'm asking you guys what matters, then it, then something more meaningful will come out of it(?) Some more meaningful information, and... something that maybe can help other parents ((mmhm)), and professionals along the way. Um, so that's kind of why I decided to do it, and um, you know, also probably hoping that it would help me too ((sure)), in making sense of my own experience ((mmhm)), and, you know, kind of coping with that myself, so... So then, basically my--, I do have some questions, ((mmhm)) but I think, I think that in whatever way anybody tells me their story, I'm going to get answers to those questions. So, so my questions are, you know, how does a person make sense of this kind of loss over time? Especially since, um, you know, especially like in the period when you had your loss, there wasn't any support ((no)), there wasn't, you know, an emphasis on having a funeral, or naming the baby, or seeing the baby. I, I don't know what your experience was, but we'll get into that. ((mmhm)) But um, you know, so if, if there isn't that kind of emphasis, then it.. almost like it's not being treated as a person, you know, um, especially if they died before birth, you know ((mmhm)), then, then how does a person make sense of that, how do they grieve, and do they grieve, do they just block all of that, or~. And so, how does a person make it through that kind of experience? And, so that's, you know, the first question, and then the second question kind of came from some reading that I did, where people who had babies die in this period were saying that they changed(?). Their view of the world changed, the way that they see things had changed. Um, they felt that they became better people, more compassionate, all that kind of thing. And so I'm wondering too, I'd like to hear more about that from other people, because that hasn't been studied very much ((oh yeah)) So kind of the positive(?) ((mmhm)) out of the negative(?) If there is any ((yeah)), you know, for some people there really isn't ((mmhm)). You know, so I'd to hear stuff like that.. but, like I said, you know, I think in whatever way you tell me your story ((mmhm)), some of that will be answered, so. So then, if you're comfortable, ((yeah)) or do you have any questions about, about anything?

Deena: Not really, I'll just tell you ((yeah, yeah)), and if you don't want it--, want, and you can.. skip by those things ((sure, yeah)) that you, if I tell you things ((no)) that aren't--, you know, that you don't want to hear or whatever, ((oh)) that don't apply to this ((no, I think anything, anything fits)) (laughter) ((yeah)) Well.. um, this was from a previous marriage, ((yeah)) and he was born--, actually, he would be, he would have been 35 now, in a couple of days ((oh-h, yeah, yeah)). So ah.. I always compare him to my nephew ((mmhm)), John. ((mmhm, mmhm)) They're just about the same age ((same age, yeah.)) And I always think-

Myrna: So you were pregnant at the same time, or~?

Deena: Well, just a little after, yeah ((yeah)). And ah.. I compare it... you know, that.. if he would be living, how he would be today? ((yeah)) What would he be like, ((right)) or you know, you keep thinking these things. ((yeah)) But.. I had a very hard labour ((mmhm, mm)) And ah... I think that.. if the doctor--, I had an old doctor, he was very very old (soft laugh) ((mmm)) And he didn't--, he was--, he never had any... really consideration for his patients ((mmm)), like he was kind of.. abrupt, and, you know ((yeah, kind of cold and.. hard)) Yeah ((yeah)). And ah.. he never came, like, till the very last ((mmhm)) And then they used so many instruments on him, that he got so bruised ((mm)), his whole face was bruised and his whole back, and, and everything ((mmhm)) But he lived for 4 days ((oh, he did, yeah)). And.. they didn't know, like, they didn't know at first that he was really sick! They just thought he'd gotten bruised from the instruments ((mmhm)) And ah.. and then on Monday--, he was born on Friday morning early, and Monday ((mmhm)), they came to me, I was breast-feeding him ((mm)) and ah, they came and they said I couldn't have him! They would feed him for--, themselves. ((hm)) They didn't tell me why(?) And of course.. I was by myself ((mmhm)), my husband was very cold to the idea ((mmm)), he, he never even saw the baby, he didn't want to see the baby. ((Because they knew already that he would be sick, or~?)) Well no, he just didn't--, he just didn't go and see him! ((oh-h, mmhm)) He was very.. um.. different(?) ((mmhm)) And.. I don't know if he.. felt... he wouldn't tell me ((mmhm)), how he felt ((mm)). And he never did say anything, ((mmhm)) he just kind of blamed me for the death ((oh-h-h)), after ((oh-h)). With--, if any.. thing came up about it ((mmhm)), I never had any chance to talk to him about it, ((oh-h)) because if I said anything, then he would just get mad and.. ((mmhm)) like he would.. start swearing ((mmm)) and say different names about the baby ((oh-h, no)) and, and stuff. And actually--, the baby--, I named the baby, it was Shawn Allan ((mmhm, oh, that's nice)) And ah.... And we did have a funeral, but if it wasn't.. for my brother, ((mmhm)) and my family that helped me, because my husband wouldn't come with me to even look at the baby in the funeral home ((yeah)) He ah.. I had my brother do all the arrangements. ((mm, yeah)) And ah, he came in and ah.. when I--, after--, then after, on Monday when they, they came back to me and they said that my baby was very sick ((mmhm)), and of course they didn't tell me what was wrong ((mmhm)), but they said they'd phoned Another City, and they were phoning different doctors ((mm)), to see if they could get some help for him ((yeah)) And then they finally came to me.. oh, about 2 I guess, 2, maybe 3 o'clock in the afternoon, and they said that he was bleeding from the liver into the abdomen ((oh-h-h)), and there was no way they could stop it ((oh-h no)). And ah.. so they let me go and see him, just--, he was in the incubator, you know, he, he had tubes in his feet, ((mmhm)) in his poor little feet ((ohh)) and he was--, and arms, and he was just.. laying there, just like a white--, as white as that paper ((yeah)), because he just.. was draining all the blood out ((mmhm)). And ah.. and then I was in the The Hospital ((mmhm)) and that's where the Sisters are ((mmhm)), like they.. they work in there ((yeah)). And they came to me, and they said, without my permission, but.. they knew he wasn't going to live, and they baptized him(?) ((mmhm)) So that he was baptized, because they knew that he wasn't going to live ((yeah)). And I phoned--, I phoned home, but, back then, we never had telephones, not everybody had telephones ((mmhm, yeah)).



So I had to phone the neighbours, which was about 3 miles, 3 ½ miles from my mom's place ((mmhm)), and get them to go down and catch my dad ((mm)), so that he could run and tell my husband ((yeah)) that.. the baby was sick ((yeah)), and by the time my husband and my mom come to the hospital ((mmhm)), he was gone ((mmm)). And ah.. of course I was really taking it hard ((yeah)) and I--, my mom was a good comfort, but.. my husband wasn't ((no)) Like he.. he didn't.. seem--, like he seemed so cold, and ((yeah)).. At that time you really.. feel like you're lost(?) ((yeah)) You just.. don't know... why? You don't understand ((mmhm)), why it should be? ((why it happened, yeah)) And, they said--, the doctor came and saw me, and he said that they were treating it like a haemophiliac ((oh-h)) But ah... I don't, I don't believe it, because.. ((it's not in your family~)) It's not in both--, it's not in either families, you know, it's just something that.. you've never heard about, ((mmhm)) well, I mean I've heard about it, but ((yeah)), but.. it's something that ah.. I'm sure--, I'm sure it was just--, I'm sure he was just injured from all the~ ..((mmhm)) You know, I should have had a.. I should have had a Caesarean ((ohh)), but... back then, they didn't do things like that very often, you know ((mm, no, no)) It's quite awhile ago. And then, of course the doctor was old ((yeah)), and he--, he didn't~.. And he just said to me, "Oh well, you're young yet, you can have more." But that wasn't--, that didn't help me! ((No, not what you needed to hear)) No. Because it, it was--,.. sure, you know, I never did have any more, ((mmhm)), because I had ah.. I had two miscarriages after ((ohh, yeah)) And ah.. ((mmm)) So it was just.. not meant to be to have children, I guess ((mmhm)), I, I don't know, maybe because my marriage wasn't going to work out ((mm, mmhm)), or.. or what, you.. you just~ Like I'm quite religious, and when I think about it, I think well, God.. maybe could see further ahead than I could ((mmm)) And ah, maybe it was meant to be ((hmm)) But um... I still.. I still feel that ache in my heart that.. you know, you wish you could have had... had someone ((yeah, yeah)) You know, even if it was just the one ((yeah)) Especially when you carry him for 9 months, and you've gone through~... ((yeah)).. But ah..((you develop that.. bond pretty early)) Yeah, yeah.. you know all about it ((yeah)), yeah. So ah... yeah, I ah... and then my brother came--, well then, that night, after the baby had passed away ((mmhm)), I said to the doctor, when he came I said "well, I don't want to stay in here anymore," 'cause I was in a room with, with 3 other ladies, and they all had babies ((mmhm)) brought to them, and I wouldn't get mine ((yeah)). And I didn't want to stay in that room ((yeahh)) and see that, you know ((yeah)). So I said to the doctor, I wanted to go home! ((mmhm)) And ah, he said, "well the only way you can go home is if you stay in the city, because you can't go out any further in case you start.. haemorrhaging." ((yeah)) And.. so.. my.. husband's sister ((mmhm)), she said to me, I could come and stay with her, and my mom could come with me ((yeah)). So, my mom and I stayed with her then until--, ((mmhm)) for about three days I guess, till I was well enough to be able to go home, ((mm, yeah)). And then, my brother came in and we went down to the funeral home ((mmhm)), and made the arrangements ((mmhm.. Did you have the funeral in The City, or?)) In Home Town, in the church in Home Town ((yeah)) And ah.. he was buried, like where we lived, um, where I lived when I was first married, ah, was only about a ½ mile, the cemetery, it was on our land ((oh yeah)). And.. we buried him there, in the cemetery ((yeah)). And.. right now, his.. the.. the.. like my ex-husband, he died too, so he's buried there, beside him ((oh-h)) And I have feelings about that too ((mmhm)), because, um... why? He didn't want nothing to do with the baby before ((yeah)), you know, why didn't he go where his mom and dad are? (soft laugh) ((Did he make that decision [himself, before], or~?)) Well I don't know if he did or not, you know, I never, I never ((you--, you were divorced many years~)) Yes. Many many years ((yeah)), yeah, I've been married for 20--, 27 years ((yeah)), so.. to this husband, and he's wonderful, so... ((yeah)).. But ah... yeah, he-, ((so a lot of-, sorry.. a lot of anger around the way he~)) A lot of anger, yeah ((yeah)), because I had no one, like.. I lived--, we lived in--, we never had power or running water ((mmhm)) or nothing, we just had to, you know, do everything ((mmhm)), the old way, eh. ((yeah)) And ah.. I tried hard... to.. to cope with it ((yeah)) and there--, but there was nobody to.. talk to really(?) ((No)) I talked to my mom and my dad a little bit, but-- ((mmhm)) and my brother,

of course, he was good. ((mmhm)) And Joan ((mmhm)). But.. still.. you know if you could have talked to your husband ((yeah)) about it, ((right)) and if he would have.. understood a little bit more ((mmhm)), the feeling you were going through, ((mmhm)) because.. I think a mother is--, when you go through that, you really.. bond fast, and ((yeah, yeah)) you just... can't believe it, so ((yeah. Well, and especially back then, I don't think um, fathers were as involved as they are now)) No- ((It might be a little different now for fathers, but-)) I think so, yeah ((yeah, but then, no, they didn't~)) They--, and nowadays, the babies room-in and everything ((yeah)), and they--, the dads are right there with them, you know ((yeah, yeah)), when they are born. ((And the dads see the ultrasounds and all that stuff)) yeah ((you know, they kind of get that.. contact a little earlier)) that's right, yeah ((yeah. So, so then you didn't get--, I mean, you didn't just not get support from him, you, you also were.. abused in a way)) I was--, yes I was, ((yeah)) because, um.. I know that, like, I wanted to have a.. cover for his grave ((mmhm)).. and ah.. ((for your baby's~)) For my baby's grave, yeah ((yeah, yeah)) And ah.. I was--, I worked. And I said, well I was going to pay for it. But the guy that was doing it for me had--, said that he'd do it on payments, like I could just give him.. payments, you know, every month, or however I wanted to do it, and I could pay for it. And.. one time he--, my husband got the mail and he opened my letter, and he--, and he said, he threw it at me and he said (angry voice) "Pay your goddamn bastard's bill!"... And that just hurt so bad, because he wasn't~ ((no)) He didn't have any right to say that (emotion, spoken quietly) ((no, no)) And that really hurt ((oh-h, how awful))...So.. that's the way he treated me ((mmhm)), like he was, he was.. he was an alcoholic, he turned out to be an alcoholic, so ((before, or~?)) No, after ((after, mmhm)) Yeah. Yeah. So ah.... When we were first married he was pretty good, but ((mmhm)), it seemed like, I don't know, it changed. Maybe--, I know he told one of the neighbors that he said maybe it would have been better if he would have lived ((mm)) Things would have gone better for us. But I, I don't know ((mmhm)), because.. maybe..

Myrna: Was he--, ..so he became like that after.. after the baby died? ((yes, yeah)) He wasn't mean before?

Deena: He wasn't that bad before, no ((okay, yeah)) He just kind of... resented me, I think ((mmhm, wow)).. For--, and I mean, blamed me, I think ((mmhm)), for my part in it, and~

Myrna: yeah. As if you had any part in it. You had no control over it

Deena: Yeah. I had no control, no ((yeah)) I.. ((that's just the way he.. dealt with it I guess..)) I guess so, yeah, or- ((or didn't deal with it)) Yeah. ((yeah)) Yeah, so ah...

Myrna: That was.. awful, I mean, very hurtful, or~

Deena: It was very hard, for me ((yeah)) And.. like, to go home.. I stayed with my mom for a little while, my mom and dad. And then to go home.. um.. I was all alone ((yeah)) And I had.. the baby things, you know. And.. that was very hard ((mmhm)) 'Cause ah.. you have to put them away again, and ((mmhm)).. get them all done up

Myrna: Did you put all that away early, or did you keep it out for awhile ((no-)) I know some people, they, you know, their families trying to.. mean well, they go and rush in and pack it all away ((yeah)) and don't give the mom a chance

Deena: No-o, I did my--, I did it myself ((yeah, yeah, good)) and ah... yeah pretty well- ((would you have preferred for someone else to?)) No. I don't think so ((yeah)) I was.. I like to do that myself ((yeah)), and just~.. And I, I kept the things for a long time, ((mmhm)), because I thought,

well.. maybe ((yeah)), you know, some day you'd.. get to use it or something ((mmhm)). And um... ((And then that extra disappointment of not.. having any more, after..)) Yeah, yeah ((yeah)). Yeah, going through those~.. I spent Christmas in the hospital one--, one year because of a miscarriage ((mmm...How far along were you when~?)) I was about 3 ½, 4 months the first one, ((yeah)) and then the second one was about 2 ½ ((wow, yeah)) Yeah. ((So how did you~.. how would you compare--, well I guess, you know, it's hard to compare, but.. how, how were those~)) Well the first one... really...um...kind of hurt a lot ((yeah)), because.. um, it was further along ((yeah)) And I...you know, I was so-o, um.. naïve.. back then. Like I, now I think of all the questions I would have wanted to ask the doctor ((yeah)). Because I had a good doctor then ((yeah)), I had a very good doctor. And I could have asked him anything. But I.. I was just so.. dumb (soft laugh), I just.. ((no)) You know, questions like.. I don't even know if it was a boy or a girl, and they could have told me ((yeah, yeah)). You know. ((But it was that time period too, they didn't volunteer those answers)) No! ((and.. they didn't encourage you even to ask, and~.. wow)) No.. no they didn't. ((no))... And I keep thinking that.. well I.. like, if.. if that one would have lived, if--, and maybe it was a girl, I don't know ((yeah)) But then it would have been the same age as Kim ((ohh)) So then I compare again (emotion), which is.. you know, kind of~.. I mean, Kim and John are like.. my kids. (soft laugh) I'm pretty proud of them (emotion) ((yeah)) Yeah... ((yeah, you would keep watching them throughout their lives and)) Oh, you do ((and always be wondering~)) Yeah, you're always... you think, well, would he be as.. talented, or, ah, would he have turned out as good as ((yeah)) these kids did, and.. you know, you wonder.. what kind of a background, he--, ((yeah)), if he would have been involved more, like with his dad, ((mmhm)) or.. you know, if he would have taken after him, or~ ((mm, yeah)).. You d--, you don't know these things ((no)) It's something that you just ask, and.. stays in the back of your mind, sort of ((mmhm..Do you think about.. that a lot?-)) I do- ((Do you think about him a lot?)) I do think of him a lot ((mmhm, yeah)) yeah, yeah, I do. ((mmhm)) Um.. especially when I see babies. ((yeah)) Then I think, well.. I had my own, but... I imagine you can~ (sigh) ((Didn't get a chance to, to parent)) No ((even though you are a mom)) Yeah. That's right. ((yeah)) Like especially, too, ah.. people will talk nowadays about, um.. you know, all the.. like the younger moms and that, how they went through--, what they went through and stuff. And.. well I went through it too, but nobody realizes that I did(?) ((Yeah, yeah)) You know

Myrna: yeah. When people ask you if you have children, what do you say?

Deena: Well I--, I'll usually, like if it's a doctor or something, I just usually say, no I haven't, but I have, I had... and I lost them ((yeah)) And ah.. ((do you include the miscarriages~?)) Oh I do. ((yeah)) Yeah, I do. ((yeah))... Because.. they were.. a start of a family too ((yeah)).. so~.. babies...

Myrna: Yeah.. If.. if someone that you don't know asks you--, like, I mean, more on a social level – asks you if you have children, do you, do you talk about~?

Deena: I don't--, no I don't usually say, then I usually just say, no I have step-children, 'cause I have 4..((yeah)) grown step-children, from my.. other.. my second marriage now ((mmhm)) And.. they're all wonderful kids ((mm)), like, they're just~.. we are.. pretty close ((close, yeah)) Yeah.

Myrna: Did you help to raise them, or were they already grown?

Deena: No, they were all grown up. ((yeah)) Well the.. the last boy, he wasn't married yet when we got married, but he got married two weeks after ((oh yeah)) So he.. he never was with us either, ((yeah)) they were just on their own ((yeah)) But they've all accepted me well ((mmhm)) And ah.. never ever... you know, would never c--, I mean, they always, when I invited them, or

even when I don't invite them, they come.. ((mmhm)) to see, to visit, you know, and.. whatever ((yeah, yeah.. that's good)).. So ah.. and they're good to me ((mmhm, mmhm)) And my grandchildren are good ((mmhm)) They're all.. they're all very good ((yeah)). But ah.. you know, they call me Grandma ((mmhm)) And ah.. they're very close to me ((good, yeah)) Yeah. 'Cause they were--, I've.. been their grandma ((mmhm)), ever since they were born ((yeah, yeah)). And there's.. the others, that are older, um.. ((mmhm)), they will say, well, "this is Grandma Deena" ((mmhm)), or something like that, you know ((yeah, yeah)). So they--, and I'm Grandma to the kids ((mmhm)). To the great-grandchildren ((okay)), they call me Grandma. It's nice that way, that..((mmhm)) that ah... you know, I've got grandchildren, and great-grandchildren ((yeah)), little ones around ((yeah)), they're.. pretty busy, but ((yeah)) they're nice ((yeah, right. Good)) Yeah. But ah.... I still think.. back, when I, when I see babies ((mmhm)), and.. when I hold them ((yeah)).. that I~.. you know... ((something that will-)) Maybe I, maybe I could have done something more, for him, I don't know ((mmm)), you know. But it--, (sigh) my hands were tied (overlapping) ((you blame yourself too, or~?)) Well, in a way I wonder if I, never--, if I would have noticed it more(?) If I would have taken--, paid more attention to him, sooner(?) ((mmm)) But I, I don't know, you see, ((mmhm)) I'm not, like I~...

Myrna: I think, I think all mothers go through that ((maybe)) yeah, blaming themselves, even though.. ((there isn't anything you can do, eh)) yeah. But it's.. beyond logic? ((yeah)) You know, like that kind of guilt is beyond logic(?) You know, even if a doctor tells you repeatedly (breath) there's nothing you could have done.. you kind of still feel those.. ((yeah)) have those feelings I guess ((mmhm)) yeah ((yeah)) so... So how did you, how did you.. cope with that, how did you.. did you ever come to any peace with those kinds of thoughts, or~?

Deena: Well... not.. not really, I have never.. really said.. that I could forget it. ((yeah)) I still think about it ((yeah)) But I think if I could have.. talked it out more ((yeah))... Even back then, if you could have had a counsellor ((mmhm)), it would have helped a lot, ((yeah)) to go.

Myrna: Did you ever.. see--, you know, talk to a counsellor, later on?

Deena: I--, later on I had talked to counsellors, yeah ((about, about this)) About different--, about things like that, and--, because my nerves are bad, eh ((yeah)). And I had depression, and ah ((mmhm)).. some of it I think relates back, maybe, to some of that part too ((mmhm)). Because... you take.. and carry it with you for so long, and finally it comes out a little bit ((mmhm.. have nobody to--, no one to talk to)) No ((about it, and then it.. kind of bubbles over, eventually)) Yeah. That's right. You can't keep it under control all the time ((yeah)) it.. wouldn't~.. it's in the back of your mind I guess ((mmhm.. Do, do you feel like you had the chance to grieve.. at.. any time?)) I don't think I had.. I really had a lot of~, no, I don't ((yeah)). Like.. not openly. ((mmhm)) By myself a little, but.. not.. not the.. not the really.. how I should ((mmhm)), I don't think. ((Like comparing to loss of an older person)) Yeah ((would you, would you say you.. woul--, you know, wouldn't be able to.. weren't able to grieve like you might, for an older person?)) I don't think.. um ((yeah)) yeah... I can't remember that I really grieved that much, like I didn't have a.. a real--, I kind of put it in the back of my mind ((yeah)) because I couldn't talk about it(?) ((yeah)), to anybody, really ((yeah)), to that many. And everybody shut up. Like they never, they never.. questioned me about anything ((mmhm)), they never asked me.. how I felt ((yeah)), or.. or anything about my feelings ((yeah)). It was just um.. kind of like.. it's all over(?) ((mmhm)), [everything]... that's it, the door's shut ((mmhm)) But it's not. Not to the one that's gone through it.

Myrna: Yeah.. How about, as the years have gone on, have you had any more--, any of that.. kind of support, anyone asking, or~?

Deena: Well.. not really, no. ((no)) My mom, a little bit, will often mention ah ((mm)), you know, if Shawn would have lived now, he.. maybe we would have been this.. ((yeah)) or that, or, or.. different things ((mmhm)). When he wa--, especially when he was littler, when he would have been.. smaller, then she says, well, she would have been babysitting him ((ohh)), you know, things like that.. she.. she was good

Myrna: mm.. And so that was helpful then, it was~?

Deena: That was helpful, yeah, mmhm, ((yeah)) Yeah. To know that.. somebody really~.. um.. I think the biggest part of... ah.. a lot of it is that.. I feel that people don't think I went through anything(?) ((yeah, yeah)) I--, that it was just.. ((they kind of forget it, yeah)) Yeah. ((yeah)) And ah... I even feel that way with my miscarriages ((yeah)), because it was.. it--, there was no grieving ((yeah)) you know ((yeah. No acknowledgement by other people)) No. No. ((yeah)) No.. It was just.. something that happened, and you forgot about it, and.. no one- ((everyone else forgot about it, but you didn't, right?)) everyone--, yeah, that's right ((yeah)) Everybody else.. forgot. (quietly) ((yeah)) So ah...but I guess, maybe, like.. like I, I was even a little surprised with Kim, when she mentioned me doing this, because.. I didn't think that it really.. that it.. knowing that I had a baby really.. mattered that much to her(?), ((mm)), like I, I've never, I've never spoken to her about it either ((yeah)), so ((yeah. So how did you--, was it a.. good~?)) Well I thought it was kind of neat, ((yeah)) you know ((it was a good surprise then)) Yeah. It was kind of nice that she would think of me ((yeah)), and.. and.. have me do this ((mmhm)) because um... otherwise, you know, you feel kind of shut out(?) ((yeah)) You, you feel away from the world, or kind of that you hadn't--.. you had a part of it but.. no one else thinks you did(?) ((yeah. You're a mother, but nobody.. acknowledges that)) Yeah. ((or talks about it)) That's right, that's the feeling that I get so much, that um..... And-

Myrna: Do-, sorry.. ((that's fine)) Do you, do you um... at the anniversary times of the year, like when he was born, when he died, ((especially)) or like Mother's day, is that~? ((yes)) yeah ((yeah)) And do you~ ((well, even Christmas)) and Christmas, yeah ((yeah)) And do you ever, um.. get--, does anyone else.. acknowledge those days?

Deena: Not too often. My mom will think.. ((yeah)) about it, and say, well Shawn would have been that old now ((yeah)), or something like that ((yeah)), but, um... not really, no. ((mmhm. Do you do anything.. on your own, you know, privately-)) No I don't ((to mark the day)) No, no I don't ((mmhm, yeah)) I always, I, I know it, ((mmhm)), you know, I always remember it ((yeah)). And I think.. you know, when it starts coming closer, I can remember like.. um.. like it was the 15th when I went into labour.. ((yeah)) and all this kind of stuff, and.. what you went through, and.. ((yeah. So it's all very close right now)) yeah, yeah ((this time of year)) yeah it is, yeah ((yeah. What's that like, to be doing this.. at that, you know)) yeah, especially at- ((the 15th, 17th)), yeah.. well... I think it, maybe is a little bit, um... more... um..... I don't know how you'd call it, I'm a little more sensitive maybe(?) ((yeah, yeah)) you know, when you think of it.. like it all happened at this time.. ((mmhm)) 35 years ago, you know ((mm, yeah)) So... it's a long time ago ((mmhm)) yeah. ((does the.. the pain feel.. any less?)) It feels better. ((yeah.. over time)) Yeah it feels better. Um.. yeah, I think I've learned.. you know that I--, to live with it. ((mm)) I mean it--, I--, um... I don't resent it... ((mmhm)) as bad, I don't think, as when I lost him and I... didn't know.. what really to do, you know ((yeah, yeah)). I felt so bad, and.. there wasn't anything ((mmhm))... anywhere to go, for help ((mmhmm)) And ev--, you know, and what I got, when I first come home, was "oh well, go ahead and have another baby right away" you know, 'cause.. ((you had that right away from everybody?)) Yeah! ((mmhm)) "That's the only way to get over it" Well.. for me it wasn't--.. sure, you can have another child, ((mmhm)) but.. it's not the same as the one



you had! ((no)) It's all--, they're all.. special ((yeah.. And you've got to wonder, would they say that if.. if he had been 5 or 6 or 10, or~)) Yeah! That's right ((yeah)) yeah. 'Cause it--, it's the same... you have the same feeling ((mm)) as if they would have been older when they'd gone, ((yeah)) because you.. you held them, you had them.. ((it's still you child)) You carried them for all that time ((yeah. People don't.. seem to consider that though)) No! They don't. ((yeah)) They just~...

Myrna: So when you say.. you know, you don't resent it as much, you.. resenting.. other people.. then, for.. the lack of support you got, or~?

Deena: Yeah, sort of, ((yeah)) yeah. I kind of--, that.. that's faded ((yeah)), you know ((yeah)) that it's not as~

Myrna: How do you view that now ((ah..)) How they reacted, or.. the lack of support?

Deena: Yeah.. um.. well I think... I feel that they could've.. they could've been.. everyone ((mm)) could have been a little bit.. more thoughtful ((mmhm)), you know.. Um.. nobody came to visit, really ((mmm)).. They just.... kind of let me be on my own ((mmhm)) and... so.. I didn't.. really~.. But now, you know, it doesn't hurt so much ((mmhm)) as it did back then, because it was so new and everything ((yeah)) Kind of learned to.. to live with it now ((yeah)).

Myrna: Some, some people have called that.. you know, where they don't come to visit you and.. it's almost as if they think you're breakable and they don't know what to say or whatever, ((well I-)) but some people call it, you know, a conspiracy of silence, ((oh yeah)) you know, it's like a taboo, ((uhhuh)) you know, nobody wants to talk about it

Deena: well, maybe that's the way they felt ((yeahh)), they thought I couldn't talk about it ((yeah)) I know my.. um, I guess this is no bearing on what you, what you're asking me ((no, that's--)) but, we lost three grandchildren, ((oh-h)) all in one, at one time ((oh-h no)), and ah.. ((mm)) .. just.. like the feeling, that I went through then ((mmhm)).. they were all killed in a car accident...And ah.. brought back.. a lot.. of feeling ((mm)) about me losing.. the baby ((mmhm)) Like I really.. I really grieved for them ((yeah)) And ah.. I think I grieved more because I had had a baby and lost one(?) ((mmhm)) And, and at that time, like.. the one that lost the two girls, ((mm)) my step-daughter, she said to me, you know, she--, then she, she said, "Well, you know what it's like, don't you" ((ohh)), and I said "yes, I do" ((yeah, yeah. So.. kind of grieved for..)) yeah ((Shawn, through--, at the same time)) that's right, yeah, mmhm ((yeah))... yeah, so.... But ah...

Myrna: Do you find that.. loss... of anybody.. is more.. more painful now? I mean I guess it's hard to know ((well)) what it was like before, but.. you know, compare, but~

Deena: yeah.. well... I think it's more um..... like you.. you notice it more, or you feel it more(?) ((mmhm)) Because.. ah..... especially when my brother passed away ((mmm)) I really~.. And I didn't.. I didn't have the time to grieve for him like I should have either, because I had to take over his job right away ((oh-h)) And ah.. I had to keep my.. mind on all my other things to do, ((yeah)) without.. just grieving for him, you know, because I had to take over his job, and that was hard(?) ((yeah)) To take over his job ((oh, for sure, yeah)) Yeah.. but ah.. for, for close people, yes, I think that I.. I do.. feel it more ((mmhm.. especially if you have any.. any.. unresolved grief yet over, over Shawn.. then)) yeah ((I would think)) that's right, yeah

Myrna: that's.. you know, maybe at times when other people pass away that are close to you, you... that.. pain over Shawn becomes.. more raw again ((yeah)) yeah

Deena: I think so, yeah. It brings it all back ((mmhm)), sort of what you went through ((mm, mmhm)) you know.. when he was... when you had to.. make up the plans for the.. funeral, and everything ((mm, it all comes back)) It all comes back, yeah

Myrna: It's interesting, you say--, before we started you said you don't remember that much, but (((laugh))), you know, I think you.. remember a lot ((well)), maybe more than you.. realized? ((maybe more than I realized, yeah)) yeah, like details too, and...((yeah)).... You know, even though you haven't been able to talk about it all that much, ((no)) it's.. all there, right?

Deena: Oh yes, it's all there, yeah ((yeah, yeah)) Yeah ((yeah))... Yeah, you still remember what he looked like, and.. ((yeah.. yeah, that's good, that doesn't fade)) No. You know, you still--, I can still remember him. (quiet, some emotion) You know, in that little bundle when he came (soft laugh) ((mmm, yeah)) Yeah.... I'll never forget, the morning that he was born... um.. after he was born I felt.. I felt good! I was.. sure, I wasn't.. I was sore, and stitched and everything, but.. I felt pretty good ((mm)), and I was hungry, 'cause I hadn't eaten for days, eh ((mmhm)) And ah, so I asked the nurse if I could have some toast and milk, or coffee, or something to drink, and they brought me some, and I just drank it and I threw it right back up again (laughter) ((oh)) I thought I felt good, but I guess I wasn't (laughter) ((yeah, a little bit too much all at once)) Yeah (laughter) so...

Myrna: Did you get to keep any mementos... of him?

Deena: Well I have some pictures ((do you? Oh good)) I have pictures of him, that they--, some people took of the, while he was in the casket ((yeah, oh-h)) Yeah, I have, I have that. And I have his funeral.. like his book, from the funeral home. ((yeah)) Um.. he just had a small white casket, a very.. you know, just a small.. ((yeah)) I imagine you know what they're like

Myrna: Ah, we didn't--, we had a cremation

Deena: Oh, you did, eh, ((yeah)) oh yeah. And ah.. and then, just the funeral home director, he carried it ((mm, oh yeah)) Because it wasn't.. needed to be.. pallbearers or anything ((mmhm))... But we did have a real.. a church funeral ((mm, that's good)).. And ah.. the neighbours were good, in the respect that way, they took up a collection(?) ((mmhm)) And gave us some money.. to help.. pay for the expenses ((yeah)). 'Cause back then there was~, I mean, it didn't cost very much, I think it was \$100 or something ((mmhm, that was a lot then, too)) You know, but it was hard to get back then ((yeah, yeah)) Yeah. So.. and we just farming, so, ((yeah)) there wasn't.. that much coming in

Myrna: mmhm... I know.. some people from that period, or before that even, they didn't.. have the chance to do those--, to have a funeral, or ((no, I suppose not)) Are you glad that you had that? ((Oh I certainly am, I certainly am)) yeah.. I mean that's--, there could be more regrets if you hadn't then, probably~

Deena: yes, if he would have just been ah~.. Like I'm not saying anything against cremation, because I think that's the way we're going to go now, ((mmhm, yeah)) is cremation ((yeah)). Um, I don't think there's anything wrong with it ((yeah)) But.. back then, they didn't(?) ((mmhm, yeah)) you know. And I think we would still have had a funeral even if it would have been a cremation



((mmhm, mmhm)). But.. um, no, I don't have--, I, I'm happy that we did have a.. a funeral for him, and ((right, yeah, yeah))

Myrna: And the pictures, is that something you're glad you have too?

Deena: Yes I am. mmhm, yes, yeah ((yeah)) ..They're ah.. you know, they're just black and white pictures ((mmhm)) because you didn't have color back then ((mmhm)), but they're just as good as.. as anything else. I don't have a lot, but I have about three of them I think ((yeah, yeah)). And ah.. you can still see him (soft laugh) ((mmhm)) ..that way ((yeah)) you know. And I go to the grave, and~ ((yeah... do you go.. often?)) I don't feel as--, no, I, I go once or.. so a year ((yeah, yeah)) But um....ah.. I don't feel.. as good to go now, with his dad there(?) ((ohh)) I feel-- , I have a resentment for that ((yeah)) Because they could have asked me, too ((mmhm)), what I thought ((mmhm.. especially--, yeah, since he didn't want to even)) But he didn't want to anything to do with the baby in the first place. ((mmm, yeah)) I think his family could have asked, ((yeah)) but they--, um, most of the won't speak to me ((mmm)) Well, I shouldn't say most of them, but half of them or so ((really)) They're very bitter. ((hm)) And um.... some of them are good, but.. ((yeah)) ah.. I guess it, it was.. their wish, or his wish, I don't know what ((hm.. but it would have been nice to have your wishes..)) Yeah! ((considered too, eh)) That's right. ((yeah)) .. I just feel like.. when you're going there, I'm, I'm not going (soft laugh) to pay respects to him, I'm, I want to pay it to my baby ((yeah, yeah)). You know, and he's right, there.. it's hard ((yeah, yeah...mm.. put up a wall.. or something!)) Yeah! (laughter) a cement wall there, so I can just go around it (laughter) ((oh, that would be.. it'd be very hard)) Yeah, but that's something I've got to.. try to get.. off my mind ((mm)), in a way, because.. it's not going to change, it's going to be there, so ((mm. It's hard to.. you don't want to.. push that to the background if you still feel that, but~)) Yeah. ((yeah)) Yeah, just that, you have that little resentment there about it, you know ((yeah, yeah. Find some way to learn live with it, I guess, is all~)) I guess so, yeah, yeah.

Myrna: Would you consider having him moved, or~?

Deena: Well I don't know ((mmhm)), I have thought about that, but then I, I have.. thought, well... I guess it doesn't really matter ((mm)) You know. ((yeah)) Where he is. But I have--, I did think of it, that.. I mean that I would someday move him to where my dad is ((mmhm)) But ah... I.. I don't imagine it will ever be, but.. I have thought about it ((mmhm)) yeah ((yeah)). I never did, until he--, they put the.. my ex there ((yeah)), and then I.. I thought.. it would have been nice if he could have been away from there. But I guess I'm just bitter ((mmhm)) That's--,... I shouldn't feel that way, but, I just-- , ((oh, that's a.. very normal feeling to have)) yeah ((yeah...mm)) ... But ah.. I'll just, like you say, have to learn to live with it ((well.. you.. do whatever works for you)) Yeah. Yeah. Well, one thing I know that I have--, I don't go as often as I should ((mm)) You know, to the grave. ((mm)) Well I don't know if I--, .. as often as I should, but as often as I did ((mm)), I should say ((mmhm)).. before, when he was by himself there. ((yeah, okay... Or maybe as often as you'd want to..)) Yeah ((if, if he wasn't there)) if he wasn't there, yeah, that's right. ((yeah)) yeah... ((that's really unfortunate.. that they did that)) Yeah. I think so too ((mmhm)), I really do, I... I ah... 'Cause that's not the cemetery that his mom and dad are at or anything, and that was not his ah.. his belief, really, that cemetery, so ((really, mm)) He should have been in the other one, I feel ((mmhm)), but then.. I'm not to say, I guess, ((mm)) I can't.. condemn somebody else ((mm)) (quieter).... I just feel that way, and I have shared that with a couple--, like my stepdaughters, ((mmhm)) that I feel that way ((yeah.. And how do they.. respond?)) They feel too ((yeah)), that I should have been able to have some say in it ((yeah)) 'Cause it.. it was my child too, that was there ((mmhm... And you're the one who cared)) Yeah! ((or showed that you cared, and he didn't)) and he didn't ((yeah)) He didn't want anything to do with him (quiet, sad sounding) ((mmm))....so.....But ah... I guess they never even--, maybe they never even

thought about it, but.. ((mmhm)).. they--.. I think I should have had a little bit of say in it (soft laugh) you know ((yeah... yeah, you should.....)) ....I don't know....

Myrna: So do you feel like.. it has.. that his death has.. affected you a lot over the years? ((It-)) Like you said before about.. your nerves and.. things like that~

Deena: Yes, I think so.

Myrna: Kind of a direct result of~ ((Yes. Yes, definitely)) And your other miscarriages too? ((mmhm)) mmhm

Deena: Yeah.. Yeah, because I never had anybody.. any.. any grieving period then at all ((yeah)) Nobody.. nobody acknowledged it ((even less than with Shawn, right)) Oh yeah, mmhm. ((yeah)) Yeah, it was just something that happened and.. ((mmhm)).. you... were supposed to get over it and keep on going, so ((yeah, mm)) And that's mainly what I did, you know, I worked, and so you.. ((mmhm)) kind of.. got back into your routine again ((mmhm)) and kind of tried to push it at the back of your mind, and ((yeah)).. go on.. but ((yeah... that's a really bad part of our society (soft laugh))) Yeah! ((that, that we expect people to do that, you know. I think with miscarriages that still happens)) Probably. ((to some extent, you know)) yeah, yeah ((yeah.. and that's not right)) No, no it's not right, it's ah... you've got the feeling there too that... it's your baby ((mmhm.. yeah))....How old was yours?

Myrna: Um, I was 8 months pregnant

Deena: Oh you were eh? Oh-h-h

Myrna: Yeah. And ah.. he died um.. about three days.. before.. I delivered.

Deena: Oh for goodness sake, eh. ((yeah. He um-)) That's sad.

Myrna: Yeah. He um.. we didn't know there was anything wrong. He had a.. what they.. we didn't know until this past summer what exactly he had(?) He had some birth defects when he was born, so we knew there was something.. But, um.. they never really told us exactly why he died, but he would have been.. quite sick if he had lived(?) ((Oh-h-h)) Um.. but then, this past summer they told us he had, um.. it's called trisomy 13 (?) Um.. Down's Syndrome, you know, ((oh yeah)) is trisomy 21 (?) ((mmhm)) And so it's just another.. what they call, um.. where the chromosomes, there's too many chromosomes, or that.. part of the genes or whatever ((oh, I see)) And so it causes these birth defects ((oh-h)) So it's, it's like one of the.. one of the most common.. kind of.. ah.. birth defects that happens(?)

Deena: mmm. And is that something that.. like happens to, to people, like they lose their babies.. before they're really~?

Myrna: Yeah.. often, often miscarriages happen {first side of tape ends, missed a few words as the tape was turned over}continue developing ((oh yeah))..during pregnancy, and so that's why some miscarriages happen. Um.. lots of miscarriages, they just don't know. ((No)) Yeah. But um.. and, and the kind that--.. um, his name was Jacob ((oh, yeah)) the kind that Jacob had ((that's nice)) thanks.. he would have, um.. not many babies have been born.. or, they might be born alive with this kind of.. problem, but then they wouldn't live past the first year of life ((oh, is that right, eh)) Yeah. It's quite a--, (overlapping) But it just happens by chance

Deena: Oh-h-h. That's sad to live with too, eh?

Myrna: Yeah..((yeah)) And it just happens by chance.. there's.. isn't any greater risk of it happening again.. for us.. than anybody else(?) ((oh, no, mmhm)) So.. but we didn't know that until this summer, so we had put off trying again, we had thought it was something else that.. would've--, the doctors first thought it was something that would've had a greater chance of happening again(?) ((oh I see, oh-h)) So we put off trying again.. and now, I'm kind of at a point where I have to finish school (soft laughter) ((oh yeah)) So we'll try again, probably next year ((uhhuh.. well, that'd be nice)) Yeah.

Deena: Hope everything goes well then. ((yeah)) I can understand how you feel, too, ((mm)) 'cause when something happens, you wonder how it's going to be the next time ((yeah.. yeah, you do)) and you have that worry, in your mind

Myrna: Yeah. Were you--, were your second pregnancies, ((yes)) second and third, they were pretty scary probably, or?

Deena: They were, yeah ((yeah)) Kind of.. um..((yeah)).. especially, when they said, you know.. haemophiliac, 'cause ah... like I- ((yeah, that does run in families, right?)) Yes, it does! ((yeah)) And you wonder, you know ((yeah)).. And then it was in the back of my mind, like.. um, would the doctor do a c-section, or, did I have to go through that.. again ((yeah)), you know ((yeah)). So... that part was.. scary too ((mmhm)).....but ah.....((yeah))..Just have to... overcome I guess

Myrna: mm...Well some--, I've read some things, I've--, um.. you know, like these kinds of losses {in late pregnancy or shortly after birth} are.. very similar.. I mean, they are.. the same as losing a child of any other age, ((mmhm)) of an older child ((oh yeah, mmhm)) And I've heard, or read.. where some parents say things like, you don't ever get over it, you just learn to live with it, or~ ((yeah, I guess so, you're-)) you know, the grief doesn't go away, ((yeah)) it just gets.. a little easier, and.. you learn to live with it(?)

Deena: Yeah. I think that's how it is ((yeah)) You still have the memories ((yeah))... you know, you think about it ((yeah)) and... and you wonder ((yeah)). But... you, you wonder if they would have been a boy or a girl, and (soft laugh) ((Yeah, yeah)) You know, I often think, what, you know, what would it have been ((yeah))... It's just... I guess it's just.. normal for people to think that sometimes

Myrna: mmhm, it is, yeah... But then if you don't get the chance to talk to somebody, maybe you would start thinking you are abnormal ((yeah)) Is that--, did that, any of that~?

Deena: Well, you wonder if there's something wrong with yourself, you know ((yeah.. since nobody else makes a big deal about it)) yeah ((you wonder why you're feeling as bad as you are?)) That's right! You really wonder ah.. why.. you feel this way, and the others don't even.. think about it, ((yeah)) you know. 'Cause ah...never mentioned. I don't think anybody ever mentioned anything about a miscarriage, my miscarriages to me ((yeah...Just tell you to go home and try again, eh)) Yeah. ((yeah)) And that's.. to me that was--, you know, right then.. that's about the last thing you want.. ((exactly)) to hear, because.. you wanted that baby.

Myrna: Yeah. If someone's husband dies, they don't say, go off and find another husband (laughter)

Deena: (laughing) Well no, that's right.

Myrna: Yeah, I think it's something abnormal with our society, not with our--, not with us, you know, feeling that way~

Deena: That, yeah, that might be, yeah

Myrna: Yeah. It's.. really unfortunate.

Deena: Yeah, it is.

Myrna: Yeah.. so.....Have you, have you noticed any changes in yourself that you would say are.. because of.. losing..~?

Deena: Well I think, um... I think I'm more sensitive to kids ((yeah)) Like I.. I um....think about.. little kids more ((mmhm)) Um.. more, more sensitive to people's feelings maybe(?) ((yeah, yeah)) 'Cause I feel.. like I feel I was.. kind of neglected, you know? ((mmm, yeah)) And I.. kind of think of people that.. go through something like that, I think it--, they should have a little bit.. of um... compassion, more compassion(?) ((yeah)) ..I know, like when we lost--, when our grandchildren died there, ah, my stepdaughter, her husband didn't want to talk about it either ((mmhm)) And she had an awful time with that ((mmm)), which I can't blame. ((mmhm)) You know. So we talked a lot, her and I. ((yeah)) 'Cause I wanted to talk, I wanted to talk as well as she wanted to talk ((yeah, yeah)) And, and I couldn't--, like, I wasn't going.. through exactly what she went through, because she lost two, but ((yeah))~ And they were teenagers ((mmhm)). But um....I still had gone through it ((yeah)) So we could.. talk about it, you know ((yeah, yeah))

Myrna: Well it's nice that.. she recognizes that ((yeah)), that you did have.. ((that's right)) you knew about it ((I felt good about that, yeah)) yeah... That she didn't say, oh well, it's not the same, yours didn't live very long, or, ((no)) you know, like that would have been really hurtful I would think

Deena: That would have been hurtful, yeah

Myrna: Yeah.. It's good that she.. recognized that

Deena: That right, yeah, it made me feel good, that we could talk about ((mmhm)) our loses, and stuff ((yeah)) But um.. that was, you know, quite a long time afterward, you know ((yeah, yeah)) It was quite a bit. Quite a bit of time had gone then ((mmhm)).. So....

Myrna: Do you.. still feel.. like if you could tell the people around you that you want them to.. remember Shawn more than they do(?), do you still have that feeling? ((sometimes)) You know, if you could talk to them and say~

Deena: "Hey, you know, I had a baby, ((yeah)) and he would have been so-and-so old now," and.. ((yeah)) you know...((yeah)) I feel that way sometimes. ((yeah)) Yeah. ((mmhm)).. Especially if, if um.. people are talking about their kids(?) ((mmhm)) You know, and you sit there and you.. ((yeah)) you don't say anything because you.. you.. haven't.. anybody that's living to.. compare with(?) ((yeah))

Myrna: What about when people talk about pregnancy and.. childbirth and all that, do you ever~?

Deena: Then I feel.. ((yeah)) what I went through ((yeah)) Like I, I go through it again, sort of thing ((yeah)) But I never ever say anything to them about it ((mmhm)). I never say, well hey, you know, I had.. a baby too, or anything ((yeah)), they just... if.. if they're talking about it I just.. really don't say anything ((mmhm))

Myrna: do you ever.. want to?

Deena: Yeah! ((yeah)) That's.. normal I think, too ((yeah, yeah)) 'Cause you have that feeling, well, you were a mom too ((yeah, yeah. You know what that.. was like)) Yeah. ((yeah)) I know even.. like.. my daughter-in-law and I went shopping one time, and, and she had just the little one then, the little girl. And we left her at home, eh. And she ah... she said--, she saw a baby in the mall, and she said, "well I've got one too, like that" (laugh) ((mm)) "mine's at home" you know. And I felt, well, gee, I had one like that too, but I didn't~ ((one too, yeah)) you know ((yeah)) So...

Myrna: Well for myself, I don't.. feel comfortable talking about~.. I'm afraid I'll make other people uncomfortable, ((yeah, that's true)) if they're talking about pregnancy and labour and stuff, and I, I pipe up and say something about my own ((mmhm)). You know, even if they know.. that I had Jacob, I, I feel that I'll make them uncomfortable if I.. mention mine

Deena: A little.. ill at ease, yeah. ((yeah)) That's the way I feel too, kind of, ((yeah)) That I feel like.. I feel like they'll think "aghh, that's just so far away, why is she even thinking about that! She never went through.. anything that.. you know, she never raised any babies or any children" ((mmhm)) That's the way I feel too, that they.. they don't really.. understand(?) ((yeah)) That there is.. still that feeling of ((mmhm))...of having a baby, and being a mom

Myrna: mmhm.... So that again.. blocks off any, any kind of support you might have ((yeah.. that's true)) yeah

Deena: Yeah... 'Cause ah.. you don't--, you're not in.. the same.. group, really, ((yeah)) or not in with the clan or whatever ((yeah, yeah.. don't fit in, quite)) Yeah.. That's right.... Did you have much recognition when you.. lost your little one?

Myrna: Um.. I think.. things are a lot better.. now. ((yeah)) Um.. but I think there's--,... So, so we had a prayer service ((uhhuh)) Um, we didn't--, the hospital didn't str--,... um,.. they, they kind of gave us our options of, of the different things we could do, so like have a funeral and a service, or have a prayer service, and you know ((uhhuh)) And, and, I mean, I had never.. known anybody who had a.. who had a stillborn baby before, so we didn't really.. know ((know)) what we should do. ((mmhm)) But we were encouraged to have something, um.. we were able to see him, we held him, ((oh, you did eh, oh-h)), and we have pictures of him and stuff, so ((oh, that's nice)) That was.. yeah, that's, I really cherish that ((yeah, I bet)) Um.. and so we had a prayer service with our families and.. you know, my husband's work friends, and my friends.. ((oh yeah, mmhm)) So, we had that, and then a little social luncheon after ((oh yeah)). So it was like a funeral ((mmhm)) , but we just didn't have a burial ((no)) Um, we, we just kept his.. um, the.. urn ((oh yeah, the urn)) the urn, ((mmhm)) yeah, we just kept that, and~.. I guess, we weren't sure, you know, if we're going to settle in City, do we want to bury him somewhere and then~, 'cause I want him buried with us ((yeah, sure)) you know, it's like you're saying, you know ((mmhm)). So we figured we'll just.. hang onto the urn for now ((mmhm)) and then, if we, you know, once we settle down then maybe have a burial ((sure)) Um...so..((yeah, that's nice)) So, but, but, yeah, a lot more support, you know, I had friends who were willing to come and talk with me ((oh yeah, that was nice, yeah)), and.. listen to me ((mmhm)), you know. And um, I.. I don't know if it's just



me, but I, I don't.. bring it up very much(?) ((mmhm)) And I guess I'm worried that, especially as time goes by, maybe people just don't want to hear about it

Deena: Well I think.. that's the way we feel, eh ((yeah)), because... I don't know why we're kind of scared to talk about it, because it is.. true, it has all happened ((yeah, yeah)) But.. it's just.. that you have no... um, no one to show.. ((yeah)), nothing to show for it, what you've gone through, really ((right, yeah))..So..

Myrna: Yeah, and it is hard to.. to tell people.. that you've just met.. you know, ((yeah)) or that you're developing a relationship with or whatever, a new friend, it's hard to bring it up ((mmhm)), and say, you know, I had a child, and.. ((that's right)) yeah ((yeah)) So..

Deena: You don't know how to.. go around.. to bring it up really, unless they approach the subject ((yeah)), and they're not.. not too likely to approach it when they don't know your history ((right, yeah)) you know ((yeah, yeah)) Yeah..

Myrna: For me, it has--, you know, doing this research, it has give--, I think it has given me a lot of support, ((oh yeah)) in that.. it's um... ((you kind of-)) if people ask me about my research, I'm able to talk about it then, and then to talk about Jacob too ((mmhm)) So.. I think that's been--, I've been really lucky to have, to have that.. ((that, that helps)) a way of--, an outlet, and then I can talk.. you know, I don't talk about Jacob with my family, but I talk about my research with them ((oh yeah)) Which is sort of.. ((uhhuh)) you know, indirectly talking about Jacob too ((sure)) so.. ((yeah)) And um.. I think I've.. because things have changed over the years, and hospitals are more.. sensitive ((mmhm)) to parents' need to grieve, and um.. and, and there's also all this.. all these books and stories out there and everything. And so I think I've felt.. um, more able to.. to do some of that stuff(?) And like mem--, doing memorial stuff, um, I sent a letter, on the first anniversary I sent a letter out to my family saying.. you know, I know we haven't talked, but I'd like you to know that I'm doing okay ((oh yeah, uhhuh)), you know, and that kind of thing. Um.. and then I did a.. website, on the internet, you know, ((oh yeah)), um, talking about Jacob and.. invited my family to read that ((oh yeah, that's nice)) So, even though we don't talk, talk about Jacob ((no, but you)), at least, you know ((mmhm)), I'm inviting them.. on paper (laugh) ((yeah, they can read)) yeah ((read about it, yeah)) yeah.. So um, I think, you know, I felt more comfortable doing that because.. there's been a shift in.. the way society thinks about these kinds of losses ((yeah, yeah)) But still not.. it's not all--, it's not completely there, you know ((No.)) They still don't-

Deena: Did your husband, was he good, was he a good.. support?

Myrna: He, he was good, yeah. He's been, he's been good ((yeah, that's good)) He's often not wanting to talk about it, but.. he'll listen to me ((uhhuh)) He doesn't talk himself, but he listens ((oh yeah, well that's good)) So yeah, but that's just.. awful what you had to... what you faced ((yeah, it was-)) I can't imagine that

Deena: I guess.. um... (sigh) it was hard ((yeah))... not to have.. a support from him ((mmhm))... Because, it was, you know--, there's another too, like, with the cemetery now, with my baby there, um... where am I going? ((yeah)) .. I, I don't know if I would have went there anyway, ((mmhm)) because I want to be where my husband is now ((yeah)). But ah.. I wouldn't go there now ((no)).. for sure ((no))... 'cause.. I just.. I just wouldn't (quieter, softly) ((yeah))..... I don't know ((mm, mmhm)).. It's um.. I guess it really doesn't matter where you're buried, but.. you want to be together ((yeah)), kind of ((yeah)). Like you said, you'd want to.. have your baby with you ((yeah)), you know ((yeah, yeah)) yeah....

Myrna: You always feel that.. I mean you--, that.. after death it might not matter, but.. now it does, you know (soft laugh) ((yeah, mmhm)) You care about that now ((that's right, yeah)) yeah..... Have your, um.. just on that--, how I was saying ... that some people have said that they've changed, and their thoughts.. about life have changed. Has any of that happened for you? Like.. um... you know, some people say they never.. considered that.. this kind of thing could happen before. I mean, you know that other people lose babies, but when it happens to you, it's like.. all your ideas about how the world works kind of change, or that, you know, you're a good person, and then, you know, why did your baby die?

Deena: Yeah, I think you go through that ((yeah)) That's, that's a.. um, questions you ask, why? Why was it me? ((mmhm)) Um... you know.. ah, had he have lived, would he have been okay? ((yeah)) Or would he have been a sick baby? ((mmhm)) Um.. maybe there was something else wrong ((mmhm)).. that back then, the doctors didn't know. ((mmhm)) Maybe. Maybe, I mean with all the.. the.. tools they used, or the forceps and stuff, maybe he had brain damage ((mmm)) Who knows? You know....((yeah. Lots of.. what-ifs, or questions)) yeah. That's right. ((yeah, yeah)) .. You wonder, and then... he seemed.. he seemed healthy to me, but.. um, wherever, like when you burp him ((mmhm)), you know, after he'd nursed ((mmhm)), wherever I patted him, he turned blue ((oh-h yeah)) Because he was.. haemorrhaging inside ((oh-h)) and.. he was just... he was all... was all.. marked ((mmhm)). (quieter) And, of course, when he first come like that, and I, and I.. you know, well I was.. really dumb about everything, but I kept on saying, "what's wrong with him?!" ((mmhm)) you know, why is he so bruised, and why is he bruising more ((mmhm)), and, why--, you know ((mmhm)). "Oh that's just normal," you know ((mmm)), and... the doctor would just.. say it was nothing ((so you.. sensed that there was something but they didn't)) well I- ((they just.. brushed it aside)) Yeah! ((yeah)) But I.. I, you know... like nowadays, I'm sure that they could have done more ((mmhm)), they would have maybe sent him out.. ((yeah)), to a better hospital or something ((mm)) Maybe recognized it earlier? ((yeah)) That he was.. sick(?) ((mmhm)) But....

Myrna: And that, that must be hard, too, thinking that in a different time, he.. things might have been very different

Deena: Yeah. ((yeah)) Yeah. Especially the way the world is.. the knowledge we've got nowadays ((mmhm)), that.. it seems like.. ((yeah))... it's so different ((yeah))....

Myrna: So.. you said that the doctor was pretty.. insensitive, or~?

Deena: Yeah, he was ((yeah)) I mean he never had any.. very compassion ((yeah)) Um.. I can remember crying and crying, and he never... like he never.. said he--, never said he was sorry really, or anything ((mm, nothing eh)) no, no.

Myrna: What about the other staff, nurses, or like you said, the nuns?

Deena: Ah.. they didn't say too much ((mm)). The sisters were good ((mmhm)) yeah, they were good. And there was one--, the head nurse was very good ((mmhm)) She was.. comforting ((mmhm)) But um.. they didn't say much ((no)) you know. The sisters, well that--, you know, they just came and said that they had--, well they took me into a room ((mmhm)) and talked with me and told me that they had baptised him and that ((mmhm)) Um.. it wasn't my religion, but it was good that they did it ((mmhm)) I thought. It was very nice ((you're glad they did that? yeah)) I'm happy they did that, yeah ((yeah)) 'Cause I have that feeling, you know, I have that knowing,



now, that he was..((mmhm)) baptised. ((mmhm)) I didn't have anything to do with it, but.. he--, he was done anyway ((yeah, yeah)). So...

Myrna: From, from.. that kind of.. religious.. point of view, did--, I know one of my other participants said she went through a lot of, um, being angry at God and.. ((oh yeah)) you know, "God, why did you let this happen?" Did you have any of that~?

Deena: Ah, no I don't think I, I was bitter that way ((no)) Um... maybe I asked, you know, in my mind, sometimes, about it ((mmhm)) But.. I have this feeling, like I have this.. this.. peace in my mind ((mmhm)) that.. there must have been something that God knew.. ((mmhm)) that I didn't know. ((mmhm)) Because maybe it was--, maybe he would have turned out to be just like his dad ((ah-h)), or maybe he wouldn't have been any--, you know, maybe he would have been sickly? ((mmhm)) Something I couldn't handle ((yeah)) you know ((mmhm)) Um... no, I don't think I blamed God, I.. ((mmhm)) I blamed myself more, I think ((oh-h)) Thinking that.. it was something wrong with me ((mmm)) Especially when I.. had such a hard labour ((oh-h)) Like I.. I figured.. you know, why didn't I.. dilate like I should have ((oh-h)) and, um... what was wrong with me ((mm)), why didn't I--,... why wasn't I normal like other women? (soft laugh) ((oh-h.. yeah-h)) And I just....

Myrna: Things you have no control over, but you still.. you still~

Deena: Yeah.. but you think of those things that... you know, why.. questions ((yeah, yeah)).....

Myrna: So has... so then.. has religion been a comfort at all?

Deena: Yes it has ((it has, eh)) it has, yes ((feeling that maybe God.. know what's going on)) And I know that he's in heaven, ((yeah)) and he's.. he's looked after good ((yeah)) you know. That.. that um... he's not suffering ((yeah)) I, I have that assurance ((yeah)). And ah..... you know I.. I still think, what he would have been like, like I say, you know ((mmhm)) if he would have... if he would have lived. And I'm sure you've had those thoughts too ((mmhm, yeah)) At.. different times, how he would have been~

Myrna: yeah.. it's like you said with babies, but also.. children that would have been the same age as him ((yeah, yeah)) yeah ((yeah)).. He would have been this old now~ ((uhhuh... he would have been walking, and talking, and~.. yeah)) Yeah.. that doesn't--, it sounds like that never goes away then

Deena: No. ((no)) I don't think so. Not, not for me anyway, maybe some people, I don't know, ((mm, I doubt it)) but I don't think so, because.. um... it was part of you ((yeah))...

Myrna: Yeah... I um, read a story about a woman who was.. in her 80s.. who had--, she went to a support group for.. um, people who had lost a child. And.. when she first arrived there, the.. the person running it said, "are you in the right place" Because, you know, she was so much older than everybody else, and.. or, it was for people who had lost babies, specifically a baby ((oh yeah)) And um.. she said, "Yep. I.. 60 years ago I--, my son died, his name was Randy" And ah.. her husband had just died six months earlier. When, when her son was born, her husband said, "I don't ever want to hear you talk about him. ((oh-h)) I don't want to hear anything about him, ever." And ah.. so she didn't, she never talked about him all her life. And then when her husband died, that's when she went to the support group ((oh, for goodness sake, eh)) mm, I.. read a few other stories like that ((yeah)) I don't think it ever--,... that you ever forget about your.. ((no)) your

child like that ((no I don't think so either then. No. She had just kept it.. to herself, and~)) Yeah, just remembered him on her own

Deena: yeah... well, there's lots that have gone through it, and lots a person doesn't know about ((mmhm)) Just like you say, 'cause they don't talk about it ((yeah)) You know, they.. you don't know how to bring up the subject, really, 'cause it's.. ((yeah)) um.. well, something that's passed, and~..

Myrna: Yeah.. yeah.. don't want to make other people uncomfortable, or.. ((yeah)) whatever, yeah ((yeah))

Deena: 'Cause then they might not know what to say, and~ ((yeah)) mm

Myrna: I find for myself, I find that writing.. somebody, ((yeah)) that works, then at least it's said ((you release some of your emotions, yeah)) Yeah. I've been able to say what I wanted to say, but.. you know, they can read it on their own time ((mmhm)), and I don't feel like I'm.. bringing up a subject that's uncomfortable for them.. ((sure)) when we're, you know, sitting together ((mmhm... yeah, that's a good way, I never thought of that, yeah)) Yeah.. everybody just.. deals with it however they can ((mmhm.. yeah))... Another thing, I didn't write it on there {the list of counsellors and places/events of support}, but I should mention to you, um... the Saskatoon Funeral Home runs a um, Memorial Service, every year, once a year, for.. people who lost a baby, either a miscarriage, or stillbirth, or shortly after birth, like, like your son. Um.. they have that every year, and.. I can let you know about it.. ((oh, I see)) I can, I can get them to send you.. an invitation if you're interested ((oh-h)) Yeah.. it's a nice little ceremony, they--, I have never gone, but I think they have you bring a memento or something to mark--, you know, like a poem or anything ((oh, I see)), it's.. kind of a remembrance of your baby, or whatever. And so, you know, they include miscarriages too ((oh yeah)), and everything, so ((mmhm)). It's kind of a nice thing ((yeah, it would--)) you know, if you like it

Deena: Yeah, I, I don't know, it's.. quite a ways to come, just for that ((yeah, oh, for sure)) you know.. but.. could see..

Myrna: Yeah.. but it is a nice ((that's a nice idea)).. I mean, not that, that, you might--, like I've never felt the need to go either ((no)) But it.. it kind of shows you that society is kind of~ ((yeah, there is.. thinking about it, isn't it?)) yeah, yeah, a little bit more support out there ((mmhm.. yeah.. they are acknowledging that there is.. lots of people that have gone through that)) yeah, that's right ((yeah))... that's one good thing anyway

Deena: yeah, yeah.. something that's come out of it. ((yeah)).... I don't know.. what else I can tell you

Myrna: yeah.. no, I think I.. you've pretty much covered all of my questions

Deena: I.. don't--,... been very good or not

Myrna: Oh! Very.. very helpful

Deena: But ah.. I don't think--, like you say, I don't think you ever forget ((no)) And.. when you compare.. if you--, I shouldn't compare I guess, but.. they're the same ages, and.. or around the same ((yeah)) and you wonder~

Myrna: mmhm. yeah, yeah.. ((when they grow up)) that's natural, a natural thing to do ((I guess so)) There's nothing wrong with that ((hm)).. You.. said you don't mark the.. anniversary, or his birthday, or anything like that, and.. is that something that you would-

Deena: The only time I did, I did.. I put it on a calendar one year. Um.. they had.. this.. ah, Our Town put out a calendar, and you put all the dates on there with ah.. anniversaries and your birthdays and stuff like that ((oh yeah, oh yeah)) Or in memory. And I put his name in there, in memory ((yeah)) I put the name there that year ((yeah.. was that.. comforting to you?)) Well kind of ((yeah)) I figured, well, if they.. um, people would read it, they might want to--.. they might realize ((see that, yeah)) Yeah... so...

Myrna: Is that, is that a hard thing too, that other people are forgetting that.. he existed?

Deena: Kind of, yeah. ((yeah)) It is kind of a hard ((yeah)).. feeling. Because ah... it feels like.. he was never... to some other people he was never here, like he was, you know, he was~..... I don't know.. that I never had any.. children ((mmhm)) Because I have nothing to show ((yeah))

Myrna: Nice if somebody else can kind of carry on that.. memory ((yeah)) yeah ((yeah))... Um, I would just mention that, um... I don't know, everyone's different in how they.. want to deal with anniversary times and stuff like that, but, you know, I.. usually, like.. um, light a candle, or.. ((oh, yeah)) On the first anniversary, my parents came and my sister came, and we lit a candle and read a poem, and.. ((oh yeah..)) it was.. just to make it~ ((that was nice!)) yeah

Deena: Yeah. No, I've never done anything like that

Myrna: Yeah. And, you know, some people, I think, find that hard. They'd, they'd rather not do that. ((mmhm)) But.. I think.. for me, it's comforting ((yeah, mmhm.. it's kind of nice)) Yeah... and then my husband and I have a little birthday cake too.. ((oh yeah)) I know some people think that's weird, ((No, it-)) but, you know it, it was nice to do ((it's nice to remember, yeah)) yeah ((yeah))

Deena: Well, if I would have done anything like that back when I was married to my first husband ((mmhm)), he would have thought I was absolutely nuts, 'cause he said I was anyway (laugh) ((oh-h.. yeah))... and I lived with him 9 years, but it was pretty hard ((mm, I bet... yeah)) so.... ((yeah.. no support there at all)) No. Not a thing ((yeah)) I used to get--,... I used to cry and cry, ((oh-h)) I know I did, because I.. didn't know what I was going to do ((yeah, yeah)) When you're all alone. ((yeah))..... But it's different now ((mmhm)) so... It's been good ((supportive husband now)) yeah, very, very ((mm, that's good)) Like he said last night, when I couldn't get him on the phone and I finally got ahold of him, and he said, "well, you know, you spoil me so much" he said, "that I can't do anything on my own" (laughter) [personal text removed] But he, he said, "well, I'm so used to you doing everything for me, I don't know how to do anything" (laughter) ((depends on you for sure, then)) Yeah, yeah. But I don't mind, 'cause he's so good to me. ((mm, that's good, yeah)) ...Yeah... ((deserves some.. some goodness like that)) Yeah, yeah. That's for sure....

{conversation wrapped up, next step discussed; copies given, counsellors names, consent form; demographic information discussed briefly; ended with casual conversation}

END